

**Seizures: The Perceptions and Frustrations of Healthcare Providers and Traditional Health Practitioners in Namibia**

by

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### **Abstract**

There are currently no official statistics on the incidence or prevalence of psychogenic nonepileptic seizures (PNES) or epileptic seizures (ES) in Namibia. Furthermore, very little is available with respect to diagnostic and treatment guidelines for these disorders. In a developing, resource-poor country such as Namibia, providing services to people with seizures may be fraught with difficulties. In addition, providing healthcare in a multicultural setting may present its own unique challenges and opportunities. This mixed-method research study aimed to explore the perceptions and frustrations of biomedical and traditional health practitioners in managing medically explained (MES) and unexplained seizures (MUS) in Namibia. The objectives were to describe and interpret their conceptualization of seizures, the diagnostic and treatment practices used in the management of seizures and the challenges encountered in managing seizure patients.

A concurrent quantitative and qualitative design was used to investigate both the context and the experiences of healthcare providers (HCPs) and traditional health practitioners (THPs) during the diagnosis and treatment of seizures. Quantitative data were collected using two surveys that focused on gathering information on the diagnostic techniques and practices used by HCPs in the management of MES and MUS. Fifty HCPs completed these surveys and data were analysed using descriptive statistics. As part of the qualitative phases of the study, thirty healthcare providers participated in semi-structured interviews regarding PNES and ES. Eleven THPs were interviewed as part of the qualitative phase of the study. Thematic analysis was used to analyse the semi-structured interviews to identify themes and subthemes within the data. The four systems of the ecological systems theory (Bronfenbrenner, 1977; 1979) were used to conceptualize the discussion and integration of the findings.

The perceptions and frustrations of HCPs and THPs centred on the areas of diagnosis, treatment, patients and awareness. Findings pointed to a lack of knowledge and awareness regarding seizures, financial constraints that hamper access to specialized services and equipment, lack of collaboration across disciplines and between HCPs and state healthcare facilities, the recognition that the untapped potential of THPs may play a valuable role in bridging the treatment gap for seizures and a need for increased awareness and training opportunities that focus on seizures among both the public and healthcare workers.

The unique challenges that a developing country such as Namibia faces were evident in some of the subthemes that highlighted the cultural differences in how seizures are conceptualized and treated. Biomedical practitioners indicated their willingness to engage with THPs in providing culturally inclusive health services for seizure patients. This may be a first step in advocating for the formal recognition of THPs in Namibia.

This study is but a first for Namibia and opens the way for future studies to build on the findings reported here. The current study can contribute to the goals of the International League against Epilepsy and the International League against Epilepsy Psychogenic Nonepileptic Seizure Task Force by providing information on the diagnostic techniques and treatment modalities used in Namibia for the management of seizures. Secondly, the findings from the multi-layered investigation could guide policy and future research on seizures in Namibia.

Keywords: Healthcare providers, Traditional health practitioners, Psychogenic nonepileptic seizures, Epileptic Seizures, Namibia

## Opsomming

Daar is tans geen amptelike statistieke met betrekking tot die omvang of voorkomssyfer van psigogeniese nie-epileptiese toevale (PNET) of epileptiese toevale (ET) in Namibië nie. Verder is baie min beskikbaar in verband met diagnostiese en behandelingsriglyne vir hierdie toestande. In 'n ontwikkelende land soos Namibië wat 'n tekort aan hulpbronne het, is diensverskaffing aan mense wat toevale kry besaai met hindernisse. Verder kan die verskaffing van gesondheidsorg in 'n multikulturele omgewing ook unieke uitdagings en geleenthede inhou. Hierdie gemengde-metode navorsingstudie het ten doel gehad om die persepsies en frustrasies van biomediese (BGW) en tradisionele gesondheidsorgwerkers (TGW) oor die bestuur van medies verklaarde (MVT) en mediese onverklaarde toevale (MOT) in Namibië te toets. Die doel daarvan was om hulle konseptualisering, diagnostiese- en behandelingspraktyke, en uitdagings met betrekking tot toevale te beskryf en te interpreteer.

'n Gelyklopende kwantitatiewe en kwalitatiewe ontwerp is gebruik om beide die konteks en die ervaring van BGW en TGW gedurende die diagnose en behandeling van toevale te ondersoek. Kwantitatiewe data is ingesamel met behulp van twee vraelyste wat gemik was op inligting rakende die diagnostiese tegnieke en praktyke wat gebruik word deur BGW in die bestuur van MVT en MOT. Vyftig BGW het hierdie vraelyste ingevul en die data is ontleed aan die hand van beskrywende statistiek. As deel van die kwalitatiewe fase van die studie, het dertig BGW deelgeneem aan semigestruktureerde onderhoude oor PNET en ET. Elf verdere onderhoude is met TGW gedoen as deel van die kwalitatiewe fase van die studie. Tematiese analise is gebruik om die semigestruktureerde onderhoude te ontleed ten einde temas en subtemas uit die data te onttrek. Die vier stelsels van die ekologiese stelselteorie (Bronfenbrenner, 1977; 1979) is gebruik om die bespreking te konseptualiseer en om die bevindinge te integreer.

Die persepsies en frustrasies van BGW en TGW het gesentreer rondom diagnose, behandeling, pasiënte en bewustheid. Bevindinge het gedui op 'n gebrek aan kennis en bewustheid van toevale, finansiële beperkinge wat toegang tot gespesialiseerde dienste en toerusting belemmer, 'n tekort aan samewerking oor die grense van dissiplines heen en tussen BGW en die gesondheidsorgfasiliteite van die staat, die erkenning van die feit dat die ongebruikte potensiaal van TGW 'n waardevolle rol kan speel in die oorbrugging van die behandelingsgapings met betrekking tot toevale, en die nood aan bewustheid en opleidingsgeleenthede wat fokus op toevale onder beide die publiek en BGW.

Die unieke uitdagings wat 'n ontwikkelende land soos Namibië in die gesig staar het duidelik geblyk uit sommige van die subtemas wat die kulturele verskille in hoe toevale gekonseptualiseer en behandel word uitgewys het. Biomediese gesondheidsorgwerkers het hulle

bereidheid om met TGW saam te werk om kultureel inklusiewe gesondheidsorg te bied aangedui. Dit kan dalk 'n eerste stap wees in die rigting van die formele erkenning van tradisionele gesondheidsorgwerkers in Namibië.

Hierdie studie is maar 'n eerste tree vir Namibië en dit maak die pad oop vir toekomstige studies wat op die bevindinge van hierdie studie kan bou. Die studie dra eerstens by tot die doelwitte van die *International League against Epilepsy* en die *International League against Epilepsy Psychogenic Nonepileptic Seizure Task Force* deur inligting te verskaf rakende die diagnostiese tegnieke en behandelingsmodaliteite wat in Namibië gebruik word vir die bestuur van toevalle. Tweedens kan die bevindinge van hierdie komplekse ondersoek toekomstige beleid en navorsing oor toevalle in Namibië lei.

Sleutelwoorde: Gesondheidsorgverskaffers, Tradisionele gesondheidsorgwerkers, Psigogeniese nie-epileptiese toevalle, Epileptiese toevalle, Namibië

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**List of Abbreviations**

AEDs	Anti-epileptic drugs
AIDS	Acquired immunodeficiency syndrome
CBT	Cognitive behaviour therapy
CT	Computerized tomography
DSM 5	Diagnostic and Statistical Manual of Mental Disorders, 5 <sup>th</sup> Edition
EEG	Electroencephalography
EM	Explanatory model
ES	Epileptic Seizures
EST	Ecological systems theory
GP	General Practitioner
HCP	Healthcare provider
HIV	Human immunodeficiency virus
IBE	International Bureau for Epilepsy
ICD	International Classification of Diseases
ILAE	International League against Epilepsy
LMIC	Low and lower middle income countries
MES	Medically explained seizures
MRI	Magnetic resonance imaging
MUS	Medically unexplained symptoms
NES	Nonepileptic seizures
NEE	Physiologic nonepileptic events
PNES	Psychogenic nonepileptic seizures
PTSD	Post traumatic stress disorder
PWE	People/person with epilepsy
SSA	sub-Saharan Africa
TB	Tuberculosis
TF	Taskforce
THP	Traditional health practitioner

TM	Traditional medicine
vEEG	Video electroencephalography
WHO	World Health Organization

## Chapter 1: Introduction

### 1.1. Introduction and Need for the Present Study

The importance of investigating the diagnostic and treatment practices available to people with seizures cannot be overemphasized. This is because epileptic seizures (ES) affects between 65 and 70 million people across the world, and of those, between 80 and 90 per cent are found in developing countries (Ba-Diop et al., 2014; Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010). ES is, therefore, classified as the most common, chronic and severe neurological disorder in sub-Saharan Africa (SSA) and involves a major burden in terms of costs, mortality, stigma, seizure-related disability and comorbidities (Moshé, Perucca, Ryvlin, & Tomson, 2015; Winkler et al., 2010). ES are often misdiagnosed, with false positives reported in up to 30 per cent of patients (Leach, Lauder, Nicolson, & Smith, 2005; Scheepers, Clough, & Pickles, 1998; Smith, Defalla, & Chadwick, 1999). Ten to twenty per cent of patients referred to epilepsy centres have PNES (Benbadis & Hauser, 2000). Consequently, PNES is viewed as a significant neuropsychiatric condition and has an estimated prevalence of 2 to 33 per 100 000 in the general population (Benbadis & Hauser, 2000).

The International League against Epilepsy (ILAE) defines ES as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (Fisher et al., 2014, p. 476). Although PNES resembles or mimics ES, it is in reality episodes of altered experience, sensation and movement, not as a result of abnormal electrical discharges in the brain, but rather underlying psychological stressors (Bodde et al., 2009; Reuber, Pukrop, Mitchell, Bauer, & Elger, 2003; B. J. Smith, 2014). Conventionally, seizures that arise as a result of organic pathology or physiological dysfunction (physical causes) are termed ‘medically explained seizures’ (MES) whereas seizures that are unexplained by organic disease are referred to as ‘medically unexplained seizures’ (MUS) (Carson, 2000; Hatcher & Arroll, 2008; Klaus et al., 2013). As can be seen from the above two definitions, ES would be categorized as MES, you as symptoms, arise from identifiable physical causes, while PNES resorts under MUS due to the medically unexplained nature of its symptoms, which instead arise as a result of psychological (psychiatric) causes.

Low and lower middle income (LMIC) countries as based on the World Bank classification of gross national income per capita, are often poorly equipped to deal with the enormous economic, medical and social burden of ES (Radhakrishnan, 2009). Most of these resource poor countries are located in SSA, parts of Asia, Latin America and the Pacific regions and they often struggle with inefficient healthcare systems, widespread poverty and unevenly distributed material resources (Radhakrishnan, 2009). On top of that, “[t]he few efficient health care facilities that exist in these countries predominantly benefit people who reside in urban

areas and those belonging to the economically advantaged section of society, and rarely benefit the poorer sections of the population who live mostly in rural areas” (Radhakrishnan, 2009, p. 323). Namibia forms a similar picture, as secondary and tertiary healthcare is more available to the affluent urban population of Namibia than to the rural poor (Ministry of Health and Social Services, 2008).

Although the World Bank (2017) classifies Namibia as an upper middle income country, it is ranked 128 out of 168 countries in terms of its Human Development Index (HDI) (Ministry of Health and Social Services, 2013). The HDI emphasizes that economic growth should not be the only measure used to assess the development of a country, but “that people and their capabilities should be the ultimate criteria for assessing the development of a country” (United Nations Development Programme, 2016). The HDI is, therefore, “a summary measure of average achievement in key dimensions of human development: a long and healthy life, being knowledgeable and have a decent standard of living” (United Nations Development Programme, 2016). As a further illumination of the current conditions in Namibia, a GINI Index of 0.597 ranks Namibia as one of the most unequal countries in the world insofar as the distribution of income is concerned (Ministry of Health and Social Services, 2013). This is evidenced by an estimated poverty incidence of 29 per cent, with a further 15 per cent of the Namibian population living in severe poverty. The HIV/AIDS prevalence is 18.2 per cent and the unemployment rate is 27.4 per cent (Ministry of Health and Social Services, 2013). A population growth rate of 2.6 per cent, fertility rate of 3.6 per cent and life expectancy of 51.6 were reported in 2006. The percentage of households in rural areas with orphans and fostered children were 38 per cent in 2006/07. The illiteracy rate is estimated at 12 per cent (WHO Regional Office for Africa, 2010). Neurological diseases/disorders were rated as one of the top ten causes of death in outpatients in 2012 (Ministry of Health and Social Services, 2013). Tuberculosis (TB) and malaria remains prominent causes of death in Namibia. A malaria incidence of 48 per 1000 was reported in 2007 (WHO Regional Office for Africa, 2010).

Sixty-seven per cent of the population in this country in Southwestern Africa live in malaria endemic areas. It borders South Africa and has a surface area of 824 116 square kilometres. Namibia was a German colony until 1922 and thereafter essentially a colony of South Africa until 1966. From 1966 it became a protectorate of South Africa, after which it gained its independence in 1990.

The World Health Organization (WHO) estimated the Namibian population at 2 459 000 in 2015, with a population density of 2.2 persons per square kilometre (World Health Organization, 2016). Despite its relatively low population and density, Namibia is culturally diverse with nine defined ethnic groups and thirteen nationally recognized languages (Frydman, 2011). A total of 87.8 per cent of the population speak one or more of ten indigenous African

languages, including “Oshikwanyama, Oshindonga, Rukwangali, Otjiherero, Rucgiriku, Thimbukushu, Silozi, and Setswana, all belonging to the Bantu language group, and Khoekhoegowab and Ju/'hoan which belong to the Khoesan language group” (Frydman, 2011, p. 181). The remaining 11.2 per cent of the population speak one or more of three Indo-European languages, namely Afrikaans, German and English (Frydman, 2011). English, despite its minority status, is Namibia’s official language (Frydman, 2011). The majority of the population, 97 per cent, consider themselves Christian, with 50 per cent Lutheran, 20 per cent Catholic and the remainder from other denominations (US Department of State, 2015). The majority of the Himba and San ethnic groups adhere to a mixture of indigenous religious beliefs and Christianity (US Department of State, 2015). It is estimated that 10 to 20 per cent of the population continue to follow traditional African beliefs (Bialostocka, 2015).

The country is divided into 14 administrative regions, with the Khomas Region as the most central. The capital, Windhoek, is located in this region and acts as the judicial and administrative centre of the country. Windhoek is home to most of Namibia’s manufacturing industries and the business, educational, and transport sectors (Khomas Regional Council, 2015). The two largest hospitals in the country are situated in Windhoek, the Katutura Intermediate Hospital and the Windhoek Central Hospital, both state-owned and operated.

The general government expenditure on health as a percentage of total health expenditure is 60.4 per cent, while 18.65 per cent of the total health expenditure is covered by private health insurance and the remainder is out-of-pocket (World Health Organization, 2016). Namibia has 268 doctors and 66 specialists who are employed by government, three of which are psychiatrists. There are no neurologists (Ministry of Health and Social Services, 2013). According to the WHO, Namibia has 0.374 physicians per 1000 people, 12 psychiatric beds per 100 000 people, 4.78 computerized tomography (CT) units, 0.87 magnetic resonance imaging (MRI) units and 0.77 electroencephalography (EEG) monitors per million people (World Health Organization, 2016). No video-EEG (vEEG) monitors, which are the gold standard for diagnosing PNES, are available in the country.

At present, most of the studies conducted on the diagnosis and treatment of PNES or ES were performed in developed countries, with developing countries such as Namibia, receiving less attention (Chemmanam, Radhakrishnan, Sarma, & Radhakrishnan, 2009; Cronje & Pretorius, 2013; LaFrance Jr., Baker, Duncan, Goldstein, & Reuber, 2013; Whitehead & Reuber, 2012). No official statistics or diagnostic and treatment guidelines on PNES or ES are currently available for Namibia (Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016). However, two anthropological studies were conducted on traditional healthcare in Namibia and these studies include some information on the traditional treatment of seizures by a variety of traditional healers (Lebeau, 1999; Waters Lumpkin, 1993).

Even though ES is the most common neurological condition worldwide, it involves more than just seizures, and the condition is often conceptualized in more everyday terms, such as questions about independent living, uncertainties about social and employment situations and academic challenges (Institute of Medicine, 2012). The same is true for PNES, where associated stigma and loss of quality of life are compound consequences of misdiagnoses (Benbadis, 2007). Given that it takes an estimated 7.2 years to reach a definitive diagnosis of PNES, seizures are costly, to both the economy and the healthcare infrastructure (Devinsky, Gazzola, & LaFrance Jr., 2011; Pretorius & Cronje, 2015; Reuber, Fernández, Bauer, Helmstaedter, & Elger, 2002).

The successful management of seizures are therefore of extreme importance in developing countries with limited access to adequate healthcare infrastructure and manpower. As a result, it is crucial to determine the diagnostic and treatment options available to people with seizures and how the current infrastructure and skills base contend with ES and PNES. At the same time, health-seeking behaviour in Africa is a multi-layered process grounded in a kaleidoscopic range of healing styles and treatment preferences (Read, 2012; Read, Adiibokah, & Nyame, 2009). It is no different in Namibia where patterns of utilization may include a variety of healthcare modalities and depend on perceived causes or whatever healthcare treatment is available (Eastman, 2009; Lebeau, 1999; Waters Lumpkin, 1993). The aim of this study is therefore to investigate the diagnostic and treatment services offered by biomedicine and traditional medicine (TM) in order to provide an inclusive view of the known healthcare options available to patients with seizures in Namibia. Simultaneously, the study aims to identify the perceptions and experiences of the people who render these services to lay the foundation for future studies on how to improve the quality of care for seizure patients in Namibia. Towards this end, the study uses Bronfenbrenner's ecological systems theory (1977, 1979) to conceptualize the discussion of the perceptions and experiences of healthcare providers (HCPs) and traditional health practitioners (THPs) regarding the management of seizures.

The ILAE is the world's leading organization of physicians and other health professionals who work towards a world where no person's life is limited by ES (ILAE, n.d.). The organization was founded in 1909 and consists of more than 100 national chapters that aim to advance and disseminate information on ES. It also promotes research, education and training to improve services and care for patients, especially by prevention, diagnosis and treatment (ILAE, n.d.). In a further attempt to raise awareness, specifically regarding PNES, the ILAE PNES Task Force initiated a worldwide campaign to collect information on the diagnosis and treatment of PNES.

The current study can contribute to the goals of the ILAE and the ILAE PNES Task Force by providing information on the diagnostic techniques and treatment modalities used in Namibia for the management of seizures. Secondly, this multi-layered investigation could form

the basis for future investigations into government policies regarding the provision of adequate healthcare infrastructure and regulatory bodies that recognize the role of THPs in healthcare provision. Finally, the inclusion of the perspectives of THPs could contribute to later studies on how to achieve culturally inclusive healthcare services for patients with seizures.

### **1.2. Research Question**

The present study aims to explore the following question:

- What are the perceptions and frustrations of Namibian HCPs and THPs with respect to the conceptualization, diagnosis and treatment of medically explained (ES) and unexplained seizures (PNES) in Namibia?

### **1.3. Aims and Objectives**

The study sought to investigate the experiences of HCPs and THPs regarding medically explained (ES) and unexplained seizures (PNES), with a primary focus on:

- the attitudes and beliefs of HCPs and THPs regarding seizure manifestation;
- the nature of conventional diagnostic and treatment services available in Namibia for patients with seizures;
- challenges that by HCPs and THPs encounter in the management of seizures;
- post-diagnostic instructions to patients diagnosed with seizures; and
- inter- and cross-referral practices among HCPs and THPs as they relate to seizure patients.

### **1.4. Definition of Key Terms**

#### **1.4.1 Epileptic Seizures**

The ILAE defines epileptic seizures as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (Fisher et al., 2014, p. 476).

#### **1.4.2 Psychogenic Nonepileptic Seizures**

Psychogenic nonepileptic seizures (PNES) resemble epileptic seizures (ES), but are not associated with electrophysiological changes and lack a neurobiological origin (Asadi-Pooya & Sperling, 2015). It involves involuntary changes in behaviour, movement and consciousness facilitated by a dysfunction in emotion processing as a result of an unstable cognitive-emotional attention system (Baslet, 2011).

### **1.4.3 Healthcare Provider**

For the purpose of this study, a healthcare provider is an individual who is trained in biomedicine and who diagnoses, treats and/or renders clinical services to patients with seizures.

### **1.4.4 Traditional Health Practitioner**

For the purpose of this study, a traditional health practitioner is an individual who is trained or experienced in traditional African medicine and who renders services to patients with seizures. In the Namibian context, this may include faith healers or prophets who call on God to heal, herbalists and homeopaths who use traditional African herbs, diviners who tell fortunes or spirit mediums who use ancestral ceremonies and exorcism (Lebeau, 1999; Waters Lumpkin, 1993).

### **1.4.5 Perception**

According to the Oxford Dictionary of Psychology, *perception* can be defined as a “sensory experience that has been interpreted with reference to its presumed external stimulus or event and always refers to the external object that is its cause” (Colman, 2006, p. 559). The Oxford Advanced Learner’s Dictionary defines perception as “a belief or an image you have as a result of how you see or understand something” (Hornby, 2004, p. 864). For purposes of this study, perception refers to the beliefs an HCP or THP may hold about a patient’s seizures based on the HCP or THP’s understanding of the supposed origin of the seizure.

### **1.4.6 Frustration**

The Oxford Dictionary of Psychology defines frustration as “The blocking or prevention of a potentially rewarding or satisfying act or sequence of behaviour” (Colman, 2006, p. 299). According to the Oxford Advanced Learner’s Dictionary, frustration is a result of “the fact that something is preventing something or somebody from succeeding” (Hornby, 2004, p. 480). In this study, frustration describes the challenges that HCPs and THPs experience in the management of seizures.

## **1.5. Motivation for Publication Format**

Academic institutions increasingly emphasise the need for research to be published as this benefits the research community, the institution, the candidate and the supervisor (Pickering & Byrne, 2014). The research community benefits from continued publication during PhD candidature as it allows for faster, more efficient and more detailed dissemination of research results compared to other methods (Macauley & Green, 2007). Furthermore, universities boost publication output and this relates to institutional performance and greater return on investments (Macauley & Green, 2007).

For the student, publishing early in the course of the PhD candidature creates an increased sense of achievement and the resultant motivation to progress to the next phase of the research project (Pickering & Byrne, 2014). An additional advantage of this format includes the opportunity for multiple forms of feedback from supervisors, peers and journal reviewers (Kamler, 2008). Disseminating this criticism enables the student to reflect on and improve the quality of the work and to gain a better understanding of the nature of academic research (D. Jackson, 2013; Kamler, 2008). Dissertation by publication is beneficial to supervisors who may potentially benefit from co-authorship, but also from the spread of supervision workload and increased student completion (Robins & Kanowski, 2008).

In conclusion, Dowling, Gorman-Murray, Power and Luzia (2012) found that some projects, such as mixed methods research, lends itself to a publication format where related but potentially stand-alone issues all speak to a broader theme. This can be applied to the current study where the central topic revolves around seizures, both MES and MUS, as perceived by HCPs and THPs. In an effort to address the research question of this study, articles were structured to form a coherent and integrated whole, with the central premise of investigating the manifestation of seizures through the perceptions and frustrations of HCPs and THPs regarding the conceptualization, diagnosis and treatment of ES and PNES in Namibia. The dissertation comprises a general introduction, problem statement, literature review and a discussion of the research methodology. This is followed by the manuscripts of the four articles that have been submitted for publication. A final evaluative chapter that integrates the articles into a coherent whole concludes the dissertation. The following table summarizes the layout of the various chapters and the status of each of the articles in the publication process (Table 1.1).

Table 1.1. *Layout of chapters and publication status*

<b>Chapter</b>	<b>Topic</b>	<b>Publication Status</b>	<b>Authors and Title</b>
1	Introduction and motivation		
2	Literature review & theoretical framework		
3	Method, trustworthiness and ethical considerations		

4	Qualitative study on HCPs and psychogenic nonepileptic seizures	Published in <i>Seizure: European Journal of Epilepsy</i> , 50 (2017) pp. 43-52	du Toit, A., & Pretorius, C. Psychogenic nonepileptic seizures: Namibian healthcare providers' perceptions and frustrations
5	Quantitative study on diagnosis and treatment of seizures	Published in <i>Epilepsy &amp; Behavior</i> , 83 (2018) pp. 92-102	du Toit, A., & Pretorius, C. Diagnostic and treatment practices for psychogenic nonepileptic and epileptic seizures in Namibia
6	Qualitative study on HCPs and epileptic seizures	Under review at <i>Epilepsy &amp; Behavior</i> from 10 September 2017 (EB_2017_594)	du Toit, A., & Pretorius, C. Epilepsy: Namibian healthcare providers' perceptions and experiences
7	Qualitative study on THPs and seizures	Published in <i>Epilepsia Open</i> , 3(3) pp. 374-382, 2018	du Toit, A., & Pretorius, C. Seizures in Namibia: A study of traditional health practitioners
8	Conclusion, Limitations and Recommendations		

## 1.6. Chapter Exposition

Chapter 2 presents a literature review by firstly looking at the classification of seizures and then moves on to focus on the epidemiology, historical background and clinical picture of seizure disorders. It provides a closer look at factors that contribute to the aetiology and the development of seizures. The chapter thereafter continues to review the various diagnostic techniques, treatment options and prognostic factors in seizures. This is followed by an overview

of the available literature pertaining to the social and socioeconomic burden of seizures. The chapter also takes a brief look at the biomedical approach to healthcare provision and explores the literature on traditional medical practices in Namibia. Finally, Bronfenbrenner's ecological systems approach (Bronfenbrenner, 1979) is used to explore how the perceptions and frustrations of HCPs and THPs regarding seizures impact on the successful diagnosis and treatment of this disorder.

Chapter 3 outlines the research methodology that was used in this study. First, the research design and the description and selection of participants are discussed. This is followed by a description of the data collection and analysis procedures applied to the study. The chapter closes with a discussion of the processes used to ensure trustworthiness and the ethical considerations.

Chapter 4 presents the manuscript of the article that has been published in *Seizure: European Journal of Epilepsy*. This article discusses the perceptions and frustrations of HCPs regarding the diagnosis and treatment of PNES. Findings that resulted from the semi-structured interviews with HCPs are presented in this article. The perceptions and frustrations of HCPs centred on the areas of diagnosis, treatment, patients and awareness. The four systems of the ecological systems theory (Bronfenbrenner, 1977, 1979) were used to conceptualize the discussion of the subthemes and findings were linked to the existing literature on PNES. This process revealed that HCPs' perceptions and frustrations were often related to a lack of knowledge and awareness regarding the disorder. Furthermore, the lack of access to specialized services and equipment contributed to HCPs' frustrations. Delays in the diagnosis of PNES added to HCPs' concerns regarding ineffective referral practices and the subsequent increase in healthcare costs. Although HCPs expressed the need for adequate training opportunities and increased awareness about the disorder, the lack of such opportunities and awareness campaigns were identified as possible problem areas. The unique challenges that a developing country such as Namibia faces were evident in some of the subthemes that highlighted the cultural differences in how PNES are conceptualized and treated.

Chapter 5 includes the manuscript of the article submitted to *Epilepsy & Behavior*. This article presents the quantitative results of the ILAE PNES TF Survey for HCPs and the Epilepsy Survey for HCPs. The information from the surveys provides a description of the diagnostic techniques and practices used by HCPs in the management of medically explained and unexplained seizures. The purpose of the surveys was to gather data for descriptive purposes and the article therefore presents the information by means of descriptive statistics. Frequencies and percentages for the categorical variables are tabulated. Continuous variables are reported as means and ranges. Findings are reported in the form of frequency distributions and percentages, as well as means and ranges to summarize the current diagnostic and treatment regimens used by

HCPs in Namibia. The findings are based on 50 responses from healthcare practitioners involved in the management of seizures. The responses indicated that HCPs have less confidence in their ability to manage PNES than ES. Psychological/psychiatric assessments are seldom utilized. Although HCPs engage in face-to-face communication of diagnoses, they seldom refer patients to additional sources of information. HCPs follow up patients with ES more regularly than those with PNES. HCPs indicated their willingness to collaborate and recognize the role of traditional health practitioners in a supportive capacity when it comes to the management of seizures. Financial constraints, limited availability of specialized equipment and lack of knowledge and awareness regarding seizure disorders by both HCPs and patients were mentioned as major obstacles in accessing healthcare services. This study showed a commitment to the diagnosis and treatment of seizures. However, there are gaps with respect to the training of HCPs and the implementation of standardized guidelines for the management of ES and PNES.

Chapter 6 contains the manuscript that has been submitted to *Epilepsy & Behavior*. This article discusses the perceptions and frustrations of HCPs regarding the diagnosis and treatment of medically explained seizures. Fifteen HCPs from the private healthcare sector in Namibia were recruited to participate in semi-structured interviews. The semi-structured interviews were analysed using thematic analysis to identify themes and subthemes in the data. These themes were subsequently interpreted from the perspective of the different levels of Bronfenbrenner's ecological systems theory. The main themes identified in this study centre on the diagnosis, treatment, patients and knowledge about ES. It was evident from the findings that Namibian HCPs encounter several challenges in the management of people with epilepsy. The barriers that a developing country such as Namibia encounters were evident in subthemes that highlighted the widespread use of traditional health practitioners in the treatment of seizures, the lack of access to specialized equipment and services and under-resourced state health facilities. The article concluded that the compound effect of the population's low socio-economic status and lack of knowledge about ES paints a bleak picture of the current situation of epilepsy in Namibia.

Chapter 7 presents the manuscript of the article submitted to *Epilepsia Open*. This article discusses the perceptions and experiences of THPs regarding the diagnosis and treatment of seizures. Eleven THPs were identified through snowball sampling to participate in semi-structured interviews. Data from semi-structured interviews with THPs were analysed through the use of thematic analysis in order to identify, analyse and report themes across the data set. These themes were subsequently interpreted from the perspective of the different levels of Bronfenbrenner's ecological systems theory. The main themes identified in this study centre on the diagnosis, treatment, patients and knowledge about seizures. It was evident from the findings that THPs play an integral part in providing healthcare services to the poor communities in Namibia. THPs described how they customarily diagnose and treat people and the role of

witchcraft, evil spirits and supernatural forces in the causation of seizures. Diagnostic and treatment practices are described as person-specific and guided by divination and the use of plant and animal material. Treatment success is measured by the complete absence of seizures. THPs described their interactions with state healthcare facilities and expressed a need for the recognition of their practices. The article concluded that in countries with limited healthcare resources, the untapped potential of THPs might play a valuable role in bridging the treatment gap for seizures. It suggested that improved referral practices and collaboration between service providers will be to the benefit of seizure patients and required further investigation.

Chapter 8 provides an integration of the findings from the four manuscripts in this dissertation. It synthesizes the qualitative and quantitative data to form an overarching picture of how seizures are diagnosed and treated in Namibia and maps the way forward in terms of future studies. The implications and contributions of the study are discussed and limitations, researcher reflections and a last word concludes the dissertation.

## Chapter 2: Literature Review

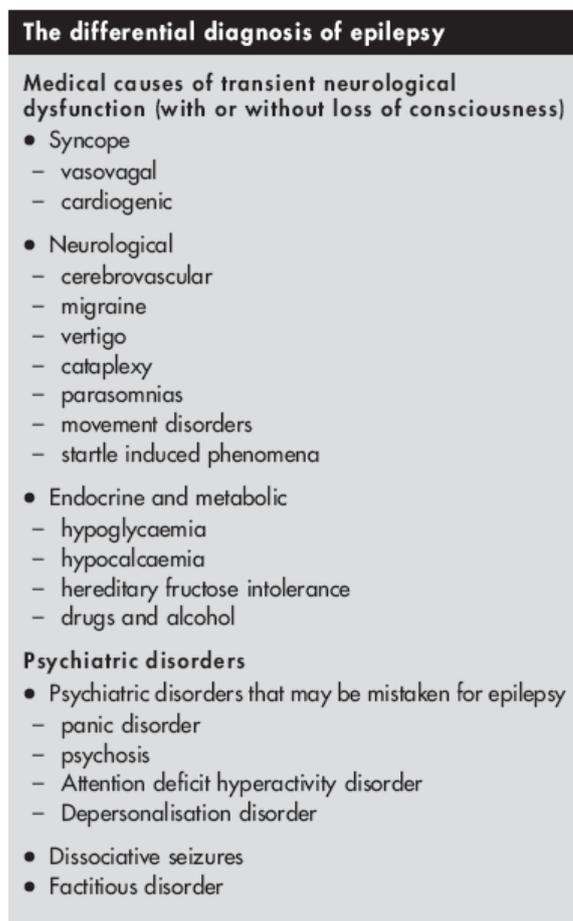
This chapter provides a review of the current literature on seizures and begins with an overview of the historical background of the condition, how biomedicine and traditional medicine conceptualize the manifestation of seizures and its classification and clinical picture. This is followed by a discussion of the aetiology and mechanisms that play a role in the development and maintenance of PNES and ES. An outline of the epidemiology, diagnostic techniques and treatment options are followed by a review of the available literature on HCPs' perceptions, experiences and their referral practices. Thereafter, a discussion of the role of THPs in the management of seizures is followed by a description of the medical and social burden of seizures and the prognosis and outcomes. The chapter concludes with a description of the ecological systems theory, which is used to interpret the findings of the study.

### 2.1. Classification of Seizures

“Seizures can be divided into three major categories: epileptic seizures (ES), PNES, or physiologic nonepileptic events (NEEs)” (Gates, 1998 as cited in LaFrance Jr., Baker, et al., 2013, p. 2005). Although PNES and ES present in a similar fashion, ES is caused by ictal epileptiform activity whereas PNES is not (LaFrance Jr. & Devinsky, 2004). Furthermore, physiologic nonepileptic events (NEEs) are “events associated with systemic alterations that produce an ictus”, but they are neither ES or PNES (LaFrance Jr., Baker, et al., 2013, p. 2006). The ILAE defines ES as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” (Fisher et al., 2014, p. 476). Although PNES resembles or mimics ES, they are in reality episodes of altered experience, sensation and movement, not as a result of abnormal electrical discharges in the brain, but rather underlying psychological stressors (Bodde et al., 2009; Reuber, Pukrop, Mitchell, et al., 2003; B. J. Smith, 2014). Conventionally, symptoms that arise as a result of organic pathology or physiological dysfunction (physical causes) are seen as ‘medically explained symptoms’ (MES), whereas symptoms that cannot be explained by organic disease is referred to as ‘medically unexplained symptoms’ (MUS) (Carson, 2000; Hatcher & Arroll, 2008; Klaus et al., 2013). As can be seen from the above two definitions, ES is defined as symptoms that arise from physical causes (MES) while PNES is described as symptoms that arise as a result of psychological (psychiatric) causes and they are therefore treated as MUS.

The distinction between the three types of seizures is primarily a clinical one based on detailed history taking and eyewitness accounts of the events (Mellers, 2005). Therefore, conditions that share the same clinical features as ES and PNES should be considered as a differential diagnosis before arriving at a conclusive decision about the origin of the seizures (see Figure 2.1). PNES resorts under dissociative seizures (DS) in this figure as it uses the

International Classification of Disorders (ICD-10) (World Health Organization, 1992), which classifies PNES as DS while the Diagnostic and Statistical Manual of Disorders (DSM 5) classifies PNES as a conversion disorder (American Psychiatric Association, 2013).



*Figure 2.1.* The differential diagnosis of epilepsy. Reproduced from the Postgraduate Medical Journal, J D C Mellers, Volume 81, pp. 498-504, 2005 with permission from BMJ Publishing Group Ltd (see Appendix A1).

The next two sections discuss the classification of ES and PNES in more detail.

**2.1.1 Epileptic seizures.** A task force of the International Bureau for Epilepsy (IBE) and the ILAE decided in 2005 to present conceptual definitions for “epileptic seizure” and “epilepsy.” The working group differentiated, between an epileptic seizure which is defined as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” and epilepsy, which is characterized by an “enduring predisposition of the brain to generate epileptic seizures, with neurobiological, cognitive, psychological, and social consequences” (Fisher et al., 2005, p. 471). However, practitioners deemed these conceptual definitions as unsuitable for everyday use due to the level of difficulty,

despite the fact that they delineate the disorder in broad terms (Moshé et al., 2015). For this reason, the ILAE task force put forward an operational definition of epilepsy, more suited for clinical use in 2013 (Fisher et al., 2014). The operational definition stipulates the following:

Epilepsy is a disease of the brain defined by any of the following conditions: (i) At least two unprovoked (or reflex) seizures occurring >24 h apart; (ii) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; and (iii) Diagnosis of an epilepsy syndrome. Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years (Fisher et al., 2014, p. 477).

In recent years, the primary site of onset of the seizure in the brain (the epileptic focus or zone) has become the way in which seizure types are classified. This change was necessitated by scientific developments (Moshé et al., 2015). The ILAE Commission on Classification and Terminology suggested in 2010 that “focal” seizures replace “partial” seizures and that the distinction between “simple” and “complex” fall away (Berg et al., 2010; Moshé et al., 2015). The new classification identifies three broad categories namely, (i) focal seizures are seizures that originate within networks limited to one hemisphere. These may be discretely localised or more widely distributed and may originate in subcortical structures; (ii) generalized seizures originate in one hemisphere and rapidly spread to bilaterally distributed networks; and (iii) unknown onset (Fisher, 2017).

Figure 2.2 below summarizes the latest ILAE classification. This operational and practical classification is based on the signs and symptoms of the various seizure types. Focal seizures are evidenced by signs and symptoms such as lip smacking, walking in circles or undressing; sudden loss of strength in one limb such as an arm or a leg; spasms, jerks or stiffening in the limbs; vigorous thrashing or pedalling movement; changes in autonomic nervous system functions such as increases or decreases in skin colour, blood pressure and heart rate; a sudden freeze or pause in movement; impaired cognition that may affect language and maths ability; changes in emotional state, such as involuntary crying, laughing or spontaneous anxiety, fear or joy; and changes in sensory perception, such as tastes, hot-cold feelings, sounds and smells. Generalized seizures often result in a combination of signs and symptoms, such as loss of awareness, incontinence, tongue biting, rhythmic jerking, loss of muscle tone and strength, spasms and stiffening of the limbs (Fisher, 2017). This seizure classification, although not yet final, makes it easier for medical practitioners to classify types that did not previously fit into any categories. In addition, the ILAE 2017 classification enhances the clarity and transparency of terminology for both the medical and nonmedical fields (Fisher, 2017).

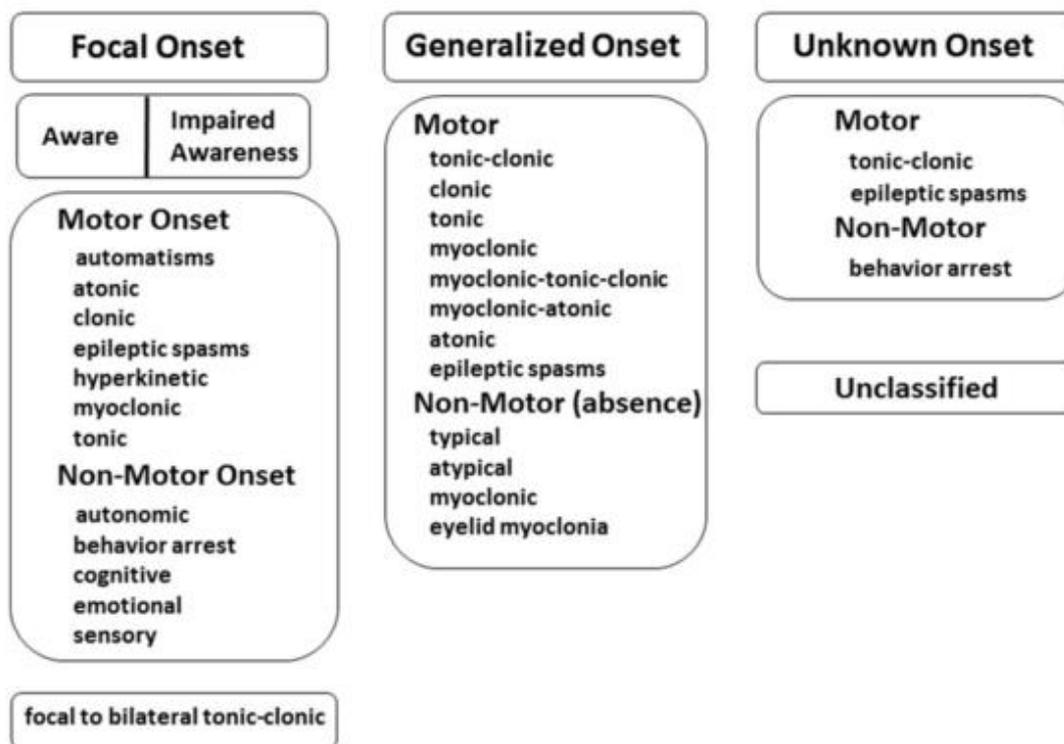


Figure 2.2. ILAE 2017 classification of seizure types expanded version. Reprinted from *Epilepsy & Behavior*, Vol: n/a, Edition: n/a, R. Fisher, An overview of the 2017 ILAE operational classification of seizure types, p. 2., Copyright (2017), with permission from Elsevier (see Appendix A2).

**2.1.2 Psychogenic nonepileptic seizures.** Unresolved semantic and philosophical dilemmas regarding the nature and aetiology of PNES hamper the classification of this condition (Griffith & Szaflarski, 2010). Questions remain as to the primary underlying aetiology of PNES; whether an aetiological approach to psychiatric classification should be used versus a descriptive method; and whether the condition should be classified as a separate disease entity or as a symptom of a psychiatric disorder (Griffith & Szaflarski, 2010). Notwithstanding these uncertainties, the DSM 5 currently classifies PNES as a type of conversion disorder, with the specific symptom type of attacks or seizures (B. J. Smith, 2014). As a result of modification to the conversion disorder criteria in the DSM 5, a more positive diagnosis can be made based on symptom presentation and by “relegating the requirements for ‘association of psychological factors’ and the ‘exclusion of feigning’ to the accompanying text” (Stone et al., 2011, p. 369). The DSM 5 Diagnostic Criteria for Conversion Disorder specifies the following (American Psychiatric Association, 2013, pp. 318–319):

- A. One or more symptoms of altered voluntary motor or sensory function.
- B. Clinical findings provide evidence of incompatibility between the symptom and recognized neurological or medical conditions.

- C. The symptom or deficit is not better explained by another medical or mental disorder.
- D. The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation.

Specify symptom type:

With weakness or paralysis

With abnormal movement (e.g., tremor, dystonic movement, myoclonus, gait disorder)

With swallowing symptoms

With speech symptoms (e.g., dysphonia, slurred speech)

With attacks or seizures

With anaesthesia or memory loss

With special sensory symptoms (e.g., visual, olfactory, or hearing disturbance)

With mixed symptoms.

Specify if:

Acute episode: Symptoms present for less than 6 months

Persistent: Symptoms present for 6 months or more.

Specify if:

With psychological stressor (specify stressor)

Without psychological stressor

This modification seems to align the DSM 5 and ICD-10, which classifies PNES under the category of dissociative disorders with convulsions (LaFrance Jr., Baker, et al., 2013; World Health Organization, 1992). Although most PNES patients with a history of abuse or trauma are classified under the conversion disorder diagnosis, further research on the usefulness of diagnostic schemes in identifying subsets of patients is needed (Griffith & Szaflarski, 2010). By subdividing patients with PNES into groups based on the results of personality testing, psychiatric diagnoses, risk factors and clinical characteristics, it may be possible to gain additional insight into the aetiology of PNES and to identify specific therapeutic interventions (Brown, Syed, Benbadis, LaFrance Jr., & Reuber, 2011; Griffith & Szaflarski, 2010).

## 2.2. Epidemiology

To date, no epidemiologic studies have been performed to determine the prevalence and incidence of epilepsy in Namibia (Angula, 2016). However, according to recent studies, epilepsy affects between 65 and 70 million people across the world (Ba-Diop et al., 2014; Ngugi et al., 2010). Of those, between 80 and 90 per cent are found in developing countries (Ba-Diop et al., 2014; Ngugi et al., 2010).

The population-based prevalence or incidence of PNES in developing countries is unknown (Asadi-Pooya & Sperling, 2015). Few studies have been conducted in this field and

none in Namibia or South Africa. The paucity of research on this subject can be ascribed to the relatively unknown nature of the disorder, as well as the diagnostic difficulties and controversy regarding the disorder itself (Cronje & Pretorius, 2013; Griffith & Szaflarski, 2010; Stone et al., 2011).

**2.2.1 Incidence.** For SSA specifically, little published information is available on the number of new cases of ES within a specific time period and in a specific population (Ba-Diop et al., 2014). A 2011 meta-analysis does report a median epilepsy incidence of 50.4/100 000/year with a high annual incidence of 81.7 per 100 000 for low- and middle income countries, compared to 45.0 per 100 000 for high income countries (Ngugi et al., 2011).

PNES incidence is reported as 4.9/100 000/per year (Duncan, Razvi, & Mulhern, 2011). This indicator of PNES incidence was recorded at a seizure clinic in Scotland between 1 January 2006 and 31 December 2008 (Duncan et al., 2011). In a study conducted at a specialist epilepsy centre between 1995 and 1998 in Hamilton County, Ohio, the mean incidence of PNES was reported as 3.03/100 000 with 4.6/100 000 in 1998 indicated as the highest incidence (J. P. Szaflarski, Ficker, Cahill, & Privitera, 2000). The increase in PNES incidence in the Ohio study may be an indication of greater awareness and familiarity with PNES among physicians, enhanced diagnostic techniques and access to vEEG equipment (Griffith & Szaflarski, 2010). In a population-based study performed in Iceland from January 1992 to December 1996, the average annual incidence of PNES is reported as 1.4 in 100 000 of the population (Sigurdardottir & Olafsson, 1998). The authors of that study estimated that about five per cent of all new-onset seizures in the Icelandic population constitute patients with PNES (Sigurdardottir & Olafsson, 1998). Although the PNES population may only constitute four per cent of that of epilepsy, a significant share of the workload of GPs, emergency personnel and neurologists are devoted to these patients due to the tendency of PNES patients to seek medical attention regularly (Hatcher & Arroll, 2008; Reuber & Elger, 2003; Robson & Lian, 2016).

**2.2.2 Prevalence.** SSA is weighed down by an epilepsy prevalence that is estimated at almost double that of North America, Europe and Asia, with median prevalence set at 14.2 per 1000 compared to 5.8 per 1000 in more developed countries (Ba-Diop et al., 2014). In developing countries the epilepsy prevalence has even been reported as high as 5-74/1000 (Preux & Druet-Cabanac, 2005). The lower prevalence of epilepsy in urban areas can be attributed to increased access to healthcare services these areas (Ngugi et al., 2010), but the variation may also be the result of risk factors that differ from region to region, such as a higher degree of parasitic infections and poor antenatal care in SSA (Ba-Diop et al., 2014; Ngugi et al., 2013; A. Singh & Trevick, 2016). The difference in prevalence between urban and rural populations in SSA is indicative of the fact that certain risk factors have a great impact. In Nigeria, an epilepsy prevalence of 20.8/1000 was found in a rural community compared to 4.7/1000 in a semi-urban

community (Osakwe, Otte, & Alo, 2014). Similarly, a high prevalence of 49/1000 was found in a study conducted in rural Rwanda (Sebera et al., 2015).

Benbadis and Hauser (2000) calculate PNES prevalence based on the percentage of patients referred to epilepsy centres in the USA and Europe and they found the prevalence rate for PNES to be between 1/50 000 and 1/3 000, or 2 to 33 per 100 000 people. In a study conducted on the total population of 62 583 in the Al-Kharga District in Egypt, 437 patients with epilepsy were identified, of which 21.9 per cent (14/64) suffered from PNES and not epilepsy (Farghaly et al., 2013). The authors ascribed the high proportion of PNES patients who was incorrectly diagnosed with ES to poor healthcare services in the area, the lack of available neurologists and diagnostic tools and resultant frequent misdiagnosis by attending GPs or non-specialists (Farghaly et al., 2013). Cultural influences on PNES type-manifestations are evident in research conducted in non-Western societies such as Turkey, Puerto Rico and India. Prevalence is reported as three to four per cent and appears to be much higher than in the general USA general population, which is reported as 0.002 to 0.03 per cent (Martinez-Taboas, Lewis-Fernandez, Sar, & Agarwal, 2010). It would be interesting to know the incidence and prevalence of PNES in Namibia. Although no information of this kind is currently available, PNES is often diagnosed at the Constantiaberg MediClinic in Cape Town, which is the closest Epilepsy Monitoring Unit to Namibia (Cronje & Pretorius, 2013).

**2.2.3 Gender.** Research does not offer evidence of gender differences in the prevalence of epilepsy, as most studies do not note a statistically significant difference (Ba-Diop et al., 2014; Institute of Medicine, 2012). In a large population-based cross-sectional study conducted in SSA, there were marginal or no differences at all in the prevalence of epilepsy in males and females, except for one centre in Kenya, which reported epilepsy prevalence as 30 per cent higher in Kenyan males compared to females (Ngugi et al., 2013). A systematic review of studies conducted in SSA on epilepsy reported a higher prevalence of epilepsy among women between the ages of 40 and 59 and among men between the ages of 20 to 39, but no gender difference in the age group 0–39 (Paul et al., 2012).

Although the majority of young adults presenting with PNES is female, gender difference favouring women is not confirmed in all variants of the disorder (Schmitz, 2010). However, females do seem to be far more common in studies from five different continents, including countries such as North America, Brazil, Argentina, Scotland, UK, Iran, India, South Africa and Australia (Asadi-Pooya & Sperling, 2015). On the other hand, a study conducted in China reports a higher PNES prevalence in males than females (An, Wu, Yan, Mu, & Zhou, 2010). Male gender and severe physical health problems are more regularly associated with late-onset PNES (Duncan et al., 2011). Furthermore, it was found that it is more challenging to diagnose PNES in males than in females and harder to confirm the diagnosis with vEEG in

males compared to females (Noe, Grade, Stonnington, Driver-Dunckley, & Locke, 2012). Confounding variables could not explain the cause for the above findings, and the researchers concluded that an alternative explanation might be worth exploring in future studies (Noe et al., 2012). Although it appears from the literature that PNES is more commonly associated with females, mean that it is late onset and cultural differences may make it more prevalent in men than previously thought.

**2.2.4 Age.** The onset of epilepsy is often in childhood or late adulthood, although it does affect people of all ages (Institute of Medicine, 2012). In SSA, a large cross-sectional study found epilepsy prevalence to be 60 per cent higher in adolescents and young adults in the age group 13 to 28 than in children aged 0–5 years (Ngugi et al., 2013). Statistics from research in Nigeria correspond, with the highest prevalence reported for the age range of 7–24 (Osakwe et al., 2014). Likewise, a systematic review of 32 SSA studies on epilepsy revealed that epilepsy prevalence peaks between ages 20 and 29 and again between ages 40 and 59 (Paul et al., 2012).

It is presumed that biographical and hormonal changes around puberty may contribute to the fact that the majority of PNES patients are young adults, with nearly 50 per cent aged between 15 and 25 years of age (Deveci et al., 2007; Reuber, 2008; Schmitz, 2010). Similarly, in a study conducted in Iran, the mean age of onset was reported as  $22.9 \pm 10.1$  years (Asadi-Pooya & Emami, 2013). Further studies report PNES in children as young as five years old and even in persons above the age of 70 years (Asadi-Pooya & Emami, 2013; Duncan et al., 2011). Interestingly, predisposing factors are somewhat different between the various age groups, with juvenile-onset patients reporting a history of abuse, academic failure and epilepsy, whereas medical comorbidities are more common among patients with adult-onset PNES (Asadi-Pooya & Emami, 2013).

**2.2.5 Demographic factors.** ES is more common in Latin America, Africa, Asia and the Eastern Mediterranean than in the rest of the world (Bhalla et al., 2014; Quet et al., 2011; World Health Organization, 2004). Risk factors that predispose these regions to a higher incidence of ES include parental consanguinity, perinatal insults, malnutrition, traumatic brain injury, HIV, Tuberculosis, Japanese encephalitis, Nipah Virus and parasitic infections such as malaria and neurocysticercosis (Ba-Diop et al., 2014; Bhalla et al., 2014; Quet et al., 2011). Mediating factors in the development of ES in these areas include low socioeconomic status and lack of specialized care (Meyer et al., 2012; M. Szaflarski, 2014). ES can be prevented through increased understanding of the possible risk factors and its role in the development of epilepsy (Ba-Diop et al., 2014). However, due to economic and social restraints, people in less developed countries often do not receive appropriate healthcare, which contributes to the increased incidence of ES in these regions (Ba-Diop et al., 2014; A. Singh & Trevick, 2016).

PNES is intricately linked to culture because of the role of social, environmental and cultural factors in the development and manifestation of the disorder (Martinez-Taboas et al., 2010). Cultural factors can therefore affect the frequency and the way in which PNES is expressed in different cultural settings (Martinez-Taboas et al., 2010). For example, the main symptoms of PNES, such as abnormal motor phenomena, alterations in consciousness and vocalization, may be interpreted as “culturally embodied metaphors that have familial, social, and political meanings and consequences that are specific to particular cultures” (Martinez-Taboas et al., 2010, p. 121). Cross-cultural differences and cross-national similarities among Middle Eastern and South Asian settings are illustrated by studies conducted in Turkey, Oman and India. An epidemiological study carried out in Turkey reported that 65.6 per cent of subjects presented with conversion disorder and fainting spells and suggests a 3.7 per cent lifetime prevalence for PNES (Deveci et al., 2007). Similar results were reported in Oman and India, where inpatients in psychiatric units received a diagnosis of conversion disorder of 71.4 per cent and 43.2 per cent respectively (Chand et al., 2000; Deka, Chaudhury, Bora, & Kalita, 2007). Again, cross-national differences and similarities in rates strongly suggest a culturally shaped phenomenon in which family and gender roles, culturally sanctioned ideas about expressing psychological trauma and traumatic exposure may all contribute to the prevalence of PNES (Martinez-Taboas et al., 2010).

### **2.3. Historical Background**

The appearance of seizures has been documented since antiquity. However, mistaken beliefs about seizures proliferated due to cultural convictions and a lack of knowledge regarding the condition (de Boer, 2010). The first recorded account of the kind of seizures that we identify as epilepsy today is described as early as 1067 – 1046 BC in Babylon, formerly Mesopotamia (Chaudhary, Duncan, & Lemieux, 2011). Supernatural forces, astrological or magical influences, evil deeds and demons are put forward as the causes for seizures in these early works (Angus-Leppan & Parsons, 2008; Chaudhary et al., 2011). As a result of its symptoms, the condition was perceived as divine or sacred and treated using spiritual practices (Chaudhary et al., 2011; de Boer, 2010). Even then, as is the case today, the social stigma attached to the condition often led to isolation, rejection and denial of education (Ba-Diop et al., 2014; Chaudhary et al., 2011; de Boer, 2010; Moshé et al., 2015).

In marked contrast to the above beliefs, a nameless monograph dated 400 BC (the Hippocratic era), *On the Sacred Disease*, argues that the divine character of epilepsy is “a shelter for ignorance and fraudulent practices” and it in truth originates in the brain (as cited in de Boer, 2010, p. 631). The author concludes that epilepsy “is no more divine than other diseases, it is hereditary, its cause lies in the brain, the releasing factors of the seizures are cold, sun and wind which change the consistency of the brain. Therefore, epilepsy can and must be treated not by

magic but by diet and drugs” (as cited in de Boer, 2010, p. 631). However, it was not until the Enlightenment period of the 17<sup>th</sup> and 18<sup>th</sup> centuries that the Hippocratic notion of epilepsy as a brain disorder established itself in the Western world (de Boer, 2010).

During the Middle Ages, seizures were often linked to phases of the moon, with Greek and Latin astrologers associating the appearance of convulsions and “falling fits” with the moon being in an “evil position” (de Boer, 2010, p. 631). Greek and Latin priests opined that “epileptics were demoniacs” and that seizures were caused by “an unclean dumb and deaf spirit” (de Boer, 2010, p. 631). Scholarly works from Persian, Chinese, Arab, Byzantine, pre-Columbian American and Roman writers added significantly to the epilepsy literature during this period (Chaudhary et al., 2011). Although most of the beliefs still centred on supernatural and celestial causes, distinctions were being made as to the origin of the seizures in the body, whether brain, stomach or other parts (Chaudhary et al., 2011). The idea that epilepsy was contagious or infectious also received its first mention in the Greek literature during this period (Chaudhary et al., 2011). A Persian writer, Avicenna, for the first time distinguished between epilepsy that arises from the brain and epilepsy that stems from the nerves in 980 to 1037 AD (Chaudhary et al., 2011). He then also suggested that treatment should focus on individual needs such as regular eating habits and “avoidance of seizure-provoking factors such as shrill noises, bright lights, and lack of sleep” (Vanzan & Paladin, 1992; Bakhtiar, Cameron & Shah, 1999 as cited in Chaudhary et al., 2011, p. 111).

The Western Renaissance (1501–1700 AD) brought advances in the understanding of the anatomy of the brain and with it new theories about the aetiology of epilepsy (Chaudhary et al., 2011). Consequently, the age-old Hippocratic concept of epilepsy as a disorder of the brain finally took root in Europe (de Boer, 2010). It was during the same period that Mandeville recorded the first detailed description of a hysterical seizure, what we know now as PNES:

As to Fits, some are seiz'd with violent Coughs; others with Hickups; and abundance of Women are taken with Convulsive laughing. There are Fits that have short Remissions, in which you would think the Woman was going to recover, and yet last many Hours. Some are so slight that the Patients only lose the Use of their Legs and Tongue, but remain sensible; others again are so violent that those who are seiz'd with them, foam at the Mouth, rave and beat their Heads against the Ground; but whether they resemble an Apoplex, or are only fainting, or seem to be Epileptick, they all come under the Denomination of Hysterick [*sic*] (Mandeville, 1730 as cited in LaFrance Jr. & Devinsky, 2004, p. 16).

The dismissal of the supernatural and the occult in the causation of epilepsy introduced the modern medical era of epilepsy during the latter part of the 19<sup>th</sup> century (Chaudhary et al., 2011; de Boer, 2010). An eminent English neuroscientist, John Hughlings Jackson, recognized

that seizures could cause alterations in consciousness, sensation and behaviour, and defined it as the extreme, infrequent and unsystematic discharge of nerve tissue on muscle (World Health Organization, 2005). One of Jackson's contemporaries, Sir William Richard Gowers, continued to distinguish between epileptic and hysterical attacks and explained ES as "more coordinated, whereas hysterical attacks had quasi-purposive movement" (Chaudhary et al., 2011, p. 113). Gowers also recommended aversive therapeutic techniques such as hydrotherapy, mild suffocation and electric shock to the skin as treatments for hysterical attacks (Krebs, 2007).

Charcot, a French neurologist, categorized nonepileptic seizures as a clinical disorder in the late 1800s, referring to it as "hysteroepilepsy" and "epileptiform hysteria" (Krebs, 2007). The continued view that the cause of these events is neurological rather than psychological in nature is evident from the treatment regimens described in the literature of the time. Charcot advocated the use of ovarian compression as a treatment option for seizures, something that was not as well received in America as in Europe (LaFrance Jr. & Devinsky, 2004). During the 20<sup>th</sup> century, the underlying causes for PNES gradually moved from theories of the body to theories of the mind (Trimble, 2010). The term *conversion* as it relates to PNES today is first described by Freud, who referred to an unconscious conflict (e.g. sexual conflict) transforming into a physical convulsion (somatic symptom) (Kozłowska, 2005). However, the singular role of intrapsychic forces in the development of hysteria was questioned after the observation of war neuroses, which required alternative explanations for hysterical symptoms (Trimble, 2010).

Much has changed since the first recorded descriptions of hysteria. Not only did the advent of vEEG as a diagnostic tool enable the medical fraternity to rule out cardiac or neurological grounds for seizure-like events, the terms used to describe this condition have also changed over the decades. Charcot's original term of *hysteroepilepsy* made way for new phrases by the late 1950s such as *hysterical seizures* and *psychogenic seizures* (Brigo, Tinazzi, & Trinka, 2015; Tannemaat & Dijk, 2015). The term *psychogenic nonepileptic seizures* have only become more prevalent since 2005, replacing *hysteroepilepsy* as the preferred term in describing this disorder (Brigo et al., 2015). However, even though the term PNES is currently the most commonly used label in the scientific literature, controversy about the most suitable name for these events remains (Brown & Reuber, 2016a). *Functional seizures* are suggested as an alternative label due to the potentially problematic way in which the term PNES distinguishes between mental and physiological processes and makes assumptions about the aetiology of these events (Brown & Reuber, 2016a). Although Brown and Reuber (2016a, p. 2) elect to use the term PNES, they regard it as "synonymous with 'dissociative seizures', 'conversion seizures', 'nonepileptic attack disorder' and (historically) 'pseudoseizures' and 'hysterical seizures'."

However, even in the 21<sup>st</sup>-century, societal ideas of ES and PNES lag behind medical concepts, and the association of seizures with divine or demonic possession, witchcraft and

mental health conditions prevails (Chaudhary et al., 2011; de Boer, 2010; Institute of Medicine, 2012). Popular beliefs that epilepsy is related to evil spirits, witchcraft, punishment from dark forces, black magic and supernatural forces are reported in studies conducted across the world (de Boer, 2010; Ekeh & Ekrikpo, 2015; Jacoby et al., 2008; Mugumbate & Mushonga, 2013; Ogunrin, Adeyekun, & Adudu, 2013; Osungbade & Siyanbade, 2011). It is evident that many misguided beliefs about the condition persist in particular parts of the world or certain cultures. In the developing countries, these ideas and the prevailing prejudice often lead to isolation and rejection and people with epilepsy (PWE) being denied an education (de Boer, 2010). The misconstructions about epilepsy “have resulted in terminology with negative and sensationalized connotations and led to cultural and societal beliefs, perceptions, and stereotypes about epilepsy that can be difficult to modify” (Institute of Medicine, 2012, p. 31).

The word epilepsy originates from the Greek term that means “to seize” or “to attack,” as it was thought that the condition “was caused by an attack from a demon or god” (Chaudhary et al., 2011, p. 109). Epilepsy-related terminology remains troublesome, even today (Noble, Robinson, Snape, & Marson, 2017; Reuber, 2014). Phrases such as “epileptic” or “epileptics” have been used traditionally. However, organizations around the world, including the Institute of Medicine (2012), now perceive the term to have judgmental and negative connotations (Noble et al., 2017). It is therefore indicated that the term “people with epilepsy” is preferred instead of “epileptics” (Institute of Medicine, 2012).

Epilepsy remains a highly stigmatized condition and the words used when referring to epilepsy may not just shape attitudes, but also reflect it (Noble et al., 2017). Furthermore, the importance of using accurate terminology to describe a condition, not only benefits patients who have to grapple with a specific diagnosis, but can also contribute towards the quality of care of PWE (Brigo et al., 2015). This is also true for PNES, where it is evident from ongoing debates in the literature that there is still much to be learned and confirmed regarding this disorder, from the precise terminology used in naming conventions to controversies surrounding aetiology, diagnosis and treatment.

#### **2.4. Clinical Picture of Seizures**

The diagnosis of seizures is fundamentally a clinical judgement based on the precise sequence of events during an attack. It therefore relies heavily on physical symptoms such as duration, recovery, habitual patterns and automatisms (Devinsky et al., 2011; Mellers, 2005). External symptoms displayed during PNES often closely resemble those of ES (Benbadis, 2005; LaFrance Jr., Baker, et al., 2013). However, unlike ES, which is caused by extreme and hypersynchronous discharges in the brain, PNES is an involuntary physical response triggered by psychological factors or trauma (LaFrance Jr., Reuber, & Goldstein, 2013). Towards this

end, a retrospective review described signs that are more frequently observed in PNES patients than in those with ES and suggests that a diagnosis of PNES were more likely when events showed a longer duration, a fluctuating course, asynchronous or side- to-side head and body movements, eye closure during the episode, ictal crying and lack of postictal confusion (Avbersek & Sisodiya, 2010)

Furthermore, PNES often lack the stereotypical movements of ES and symptom patterns and event sequences vary between ES and PNES (Krebs, 2007). Research states that the following actions can be considered significant in distinguishing PNES from ES: reports of regular seizure events with recurrent hospital admissions from a well and alert patient (Jedrzejczak, Owczarek, & Majkowski, 1999; Reuber, Pukrop, Mitchell, et al., 2003) and/or lack of response to antiepileptic drugs (AEDs) (Benbadis, 2005; LaFrance Jr., Reuber, et al., 2013).

Seizure duration is often longer in PNES than in ES, with PNES seizures regularly lasting longer than 10 minutes (Dworetzky et al., 2006; Jedrzejczak et al., 1999). However, even though exceptions may occur, seizures that last more than two minutes are often suggestive of PNES (Avbersek & Sisodiya, 2010). One of the main clinical differences between ES and PNES is the context in which the event occurs. PNES seldom occurs from sleep, although this is common in ES (31-59 per cent of events) (Avbersek & Sisodiya, 2010). Additionally, seizures that occur exclusively when the patient is alone or solely in the presence of an audience should be investigated as PNES may often occur or worsen in the presence of others (Krebs, 2007; Reuber & Elger, 2003; Shaibani & Sabbagh, 1998). Brief pauses in rhythmic movement during attacks and eyes that are closed point towards PNES, whereas the presence of postictal stertorous breathing point towards ES and can be used to distinguish between the two seizure types (Avbersek & Sisodiya, 2010; Brown et al., 2011).

Some signs and symptoms are not exclusive to either PNES or ES and are therefore less useful in discriminating between the two seizure types. One of these is the seizure onset. Benbadis (2005) state that PNES presents with slow or gradual onset or termination of the event and unusual precipitating events. However, in a study conducted by Dhiman et al. (2013), 73.2 per cent of PNES patients presented with an abrupt seizure onset, whereas only 26.8 per cent showed a more gradual onset. In conclusion, a retrospective review found that there was insufficient evidence to support the premise that PNES have a more gradual onset than ES (Avbersek & Sisodiya, 2010). Avbersek and Sisodiya (2010) also found insufficient evidence to support the premise that tongue biting and urinary incontinence occurs exclusively in ES. This viewpoint is shared by Krebs (2007), who state that there is a common misconception that tongue biting and bladder incontinence are indicators of ES, and by Shaibani and Sabbagh, (1998, p. 2490), who argue that these clinical signs “are not exclusive to epileptic seizures since they occur separately or together in about one-half of Electroencephalography (EEG)-proven

pseudoseizures.” See Table 2.1 for a summary of the features that are conventionally used to distinguish between PNES and ES. PNES is called dissociative seizures in this table as it uses the International Classification of Disorders (ICD-10) (World Health Organization, 1992) which classifies PNES as DS.

Table 2.1. *Some clinical semiological features of epileptic and dissociative seizures.*

	Dissociative seizures	Epileptic seizures
Duration over two minutes	common <sup>1 7 28-30</sup>	rare
*Stereotyped attacks	common <sup>7 31 32</sup>	common
Motor features		
Gradual onset	common <sup>7 28 31 33 34</sup>	rare
Fluctuating course	Common <sup>7</sup>	very rare
Thrashing, violent movements	common <sup>28 35-37</sup>	rare
Side to side head movement	common <sup>29 35</sup>	rare
Asynchronous movements	common <sup>29 38</sup>	very rare
Eyes closed	common <sup>28 39</sup>	rare
Pelvic thrusting	occasional <sup>1 29 40</sup>	rare
Opisthotonus, “arc de cercle”	occasional <sup>28 31 41</sup>	very rare
Automatisms	rare <sup>41</sup>	common
Weeping	occasional <sup>42 43</sup>	very rare
*Incontinence	occasional <sup>7 35 44</sup>	common
*Injury		
Biting inside of mouth	occasional <sup>7 35 39 41 44</sup>	common
Severe tongue biting†	very rare <sup>7 35 39 41 44</sup>	common
Recall for period of unresponsiveness	common <sup>1 7 41</sup>	very rare

\*Three features (“red herrings”) that are commonly misinterpreted as evidence for epilepsy have been included in this table for emphasis. Otherwise the table lists clinical features that are often useful in distinguishing DS from ES. Figures for frequency of these features are approximate: common >30%; occasional = 10%–30%; rare <10%; very rare <5%. †Injuries to the tongue in epilepsy usually involve the side of the tongue. Bite injuries to the tip of the tongue or lip are rare in epilepsy and suggest DS.<sup>39</sup>

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To describe the semiological characteristics of PNES, Dhiman et al. (2013) propose a systematic classification of seizures by using the following categories: abnormal motor response, affective/emotional behaviour phenomena, dialeptic type, nonepileptic aura and mixed pattern. This classification is based on the retrospective analysis of eighty-two patients with confirmed PNES based on vEEG recording (Dhiman et al., 2013). This classification is used to outline some of the behavioural manifestations characteristic of PNES and how it differs from ES.

**2.4.1 Abnormal motor response.** This consists of hyper motor and partial motor phenomena that include asynchronous out of phase limb movements, kicking, grabbing, thrashing, pelvic thrusting and jerking. Such responses were observed in 32.9 to 39 per cent of adult PNES patients and in 23.2 per cent of paediatric PNES patients (Dhiman et al., 2013, 2014). Other authors (Benbadis, 2005; LaFrance Jr., Baker, et al., 2013) observed convulsive or thrashing movements, pelvic thrusting, asynchronous and hyper motor movements of limbs, head, and trunk, such as side-to-side head shaking in PNES patients. In a study conducted in

China, 48.4 per cent of PNES patients experienced trembling of the extremities, while hyper motor movements were observed in 32.8 per cent of patients (An et al., 2010). Hyperventilation is seen as a partial motor response and was observed in 62.2 per cent of adult PNES patients in the Dhiman et al. (2013) study, compared to 15.6 per cent in the China study (An et al., 2010). Hyperventilation in paediatric PNES patients was observed in 12.5 per cent of cases (Dhiman et al., 2014). In a study conducted in Argentina, 21.9 per cent of PNES patients displayed signs of fear, anxiety and hyperventilation (Silva et al., 2001).

In addition, the retrospective study conducted by Avbersek and Sisodiya (2010) found insufficient evidence to support the premise that the presence of flailing and thrashing movements can be used to distinguish between ES and PNES. However, the same study confirms that asynchronous limb movements were more prevalent in PNES patients than in some types of ES, as was pelvic thrusting and side-to-side head or body movements (Avbersek & Sisodiya, 2010).

**2.4.2 Affective/emotional behaviour phenomena.** In conjunction with abnormal motor phenomena, changes in psychomotor phenomena during PNES such as stuttering, moaning, grunting, snorting, weeping and coughing were recorded (Benbadis, 2005; Dhiman et al., 2013). Vocalization was more evident during the middle of the attack at 24.4 per cent, compared to 12.2 per cent at the start of the event, with grimacing and moaning the most obvious in adults (Dhiman et al., 2013). Compared to this, vocalization at the start of the attack was found in 3.6 per cent of paediatric PNES patients with 10.7 per cent starting in the middle of the seizure and moaning and gasping being the most obvious (Dhiman et al., 2014). Similarly, a study conducted in China reported vocalization in 12.5 per cent of PNES patients (An et al., 2010). Furthermore, Avbersek and Sisodiya (2010) state that ictal crying is more specific for PNES than ES, despite its low sensitivity. Similarly, ictal stuttering seldom occurs in ES and should raise suspicion of PNES (Devinsky et al., 2011).

**2.4.3 Dialeptic type.** Although Dhiman et al. (2013, 2014) make no specific mention of loss of consciousness in adult and paediatric PNES patients, they state that 6.1 per cent of patients remained flaccid and non-responsive during the attack. Nevertheless, other authors indicate that alteration of consciousness or loss of awareness may be one of the predominant symptoms of PNES seizures (LaFrance Jr., Baker, et al., 2013; Luders et al., 1998). An et al. (2010) report that 18.8 per cent of PNES subjects were unresponsive for the duration of the seizure. Similarly, decreased responsiveness and motionlessness were observed in 19.5 per cent of PNES participants in an Argentinian study (Silva et al., 2001). However, memory recall for items presented during the period when the patient appeared unconscious proved to be higher in PNES patients than in ES patients (Avbersek & Sisodiya, 2010; Brown et al., 2011). Post-ictal confusion was also more prevalent in ES than PNES patients (Avbersek & Sisodiya, 2010).

**2.4.4 Epileptic aura.** Auras can be seen as warning symptoms and usually occur at the start of both ES and PNES (Devinsky et al., 2011). According to Dhiman et al. (2013), this can take the form of dizziness but can also be visual, auditory, abdominal or even psychic (Luders et al., 1998). Adult PNES patients more regularly report feelings of uneasiness before the event (6.1%) compared to children (3.6%) (Dhiman et al., 2013, 2014).

## **2.5. Aetiology of Epileptic Seizures**

In 2010, the ILAE revised the aetiological categories for epilepsy so that the categories are now genetic, structural/metabolic and unknown, instead of idiopathic, symptomatic and cryptogenic (Berg et al., 2010; Scheffer et al., 2014). Research on investigative technologies experienced a burst of development, providing new information on epilepsy and prompting this change (Berg et al., 2010). The term “idiopathic” has been replaced by “genetic” in which “the epilepsy is the direct result of a known or presumed genetic defect(s) in which seizures are the core symptom of the disorder” (Berg et al., 2010, p. 680). The term “structural/metabolic” describes the presence of “a distinct structural lesion that is associated with a substantially increased likelihood of developing epilepsy” (Scheffer et al., 2014, p. 8). Cortical malformations, brain tumours, trauma and stroke are cited as examples of the possible causes of structural/metabolic epilepsy (Moshé et al., 2015). Finally, an “unknown cause” is defined as “the nature of the underlying cause is as yet unknown” (Berg et al., 2010, p. 680). An “unknown cause” therefore indicates that it is not possible to make a definitive diagnosis. It does not rule out genetic defects or unrecognized disorders (Berg et al., 2010; Scheffer et al., 2014). The next section pays detailed attention to aetiological factors.

**2.5.1 Genetic factors.** Most of the severe epilepsies are thought to be the result of genetic factors, although doctors may often not be able to identify the exact mechanism and more than one genetic factor may be involved (Angus-Leppan & Parsons, 2008). Down’s syndrome may cause epilepsy at all ages and especially later in life, but apart from that chromosomal abnormalities seldom result in epilepsy (Angus-Leppan & Parsons, 2008). A small number of patients present with epilepsy due to single gene and hereditary disorders with cerebral manifestations, such as tuberous sclerosis and Dravet syndrome (Angus-Leppan & Parsons, 2008; Scheffer et al., 2014). A study in Uganda reported that 29 per cent of respondents cited genetic causes for their epilepsy (Kaddumukasa et al., 2016). There are very few genetic studies on epilepsy in adulthood, especially in Africa, but it is thought that about one third of all epilepsies have a genetic basis (Angus-Leppan & Parsons, 2008).

**2.5.2 Structural/Metabolic factors.** Structural factors refer to abnormalities in the brain that are visible during neuroimaging of the brain (Scheffer et al., 2014). Epilepsy that results from structural causes tend to show to higher mortality rates, persistent seizures and worse overall prognosis (Preux & Druet-Cabanac, 2005). Central nervous system infections, traumatic

brain injury and childhood febrile convulsions are the most frequent factors that may cause epilepsy associated with structural factors in SSA (Ba-Diop et al., 2014; Ogunrin et al., 2013). A large cross-sectional study performed in five SSA countries between 2008 and 2011, reported that 11 per cent of epilepsy cases were due to adverse perinatal events, 10 per cent to acute encephalopathy and three per cent to traumatic brain injury (Kariuki et al., 2014). A further 26 per cent of cases related to infections caused by neurocysticercosis (pork tapeworm), malaria, HIV, bacterial meningitis and tuberculosis (Ogunrin et al., 2013; Preux & Druet-Cabanac, 2005). Road accidents are the most common cause of brain injury in Africa. An estimated 17 per cent of epilepsy caused by traumatic brain injury in SSA result from work- and war-related injuries, acts of violence and active sports (Ba-Diop et al., 2014; Ogunrin et al., 2013; Preux & Druet-Cabanac, 2005). Anywhere between 1 to 36 per cent of seizures are thought to be related to perinatal causes (Ba-Diop et al., 2014; Preux & Druet-Cabanac, 2005) such as injuries suffered at birth as a result of a difficult pregnancy or childbirth. Complications at birth may lead to hypoxaemia and hypoglycaemia, which in turn may cause epilepsy (Ba-Diop et al., 2014).

**2.5.3 Other contributing factors.** Little research has been done in developed countries on the relationship between epilepsy and malnutrition (Ba-Diop et al., 2014), but a study performed in Benin did establish such a link (Crepin et al., 2007). A study conducted by Karikuiki et al. (2014) across five SSA countries, provided evidence that malnutrition was present in 14.8 per cent of PWE. In another cross-sectional SSA study, malnutrition was positively associated with epilepsy in adults (Ngugi et al., 2013). Furthermore, under-nutrition was detected in up to 25 per cent of African children with epilepsy under the age of 10 years (Kariuki et al., 2014; Quet et al., 2011). This can mean the malnutrition may be both a cause, due to insufficient micronutrients in the diet, and a consequence of epilepsy, for example, due to stigma (Crepin et al., 2007).

## 2.6. Comorbidities

**2.6.1 Psychiatric comorbidities.** PWE seemed to run a greater risk of psychiatric disorders, as is the case with many other chronic conditions (Angus-Leppan & Parsons, 2008). Epidemiologic studies have produced findings that are suggestive of a bidirectional relationship between psychiatric disorders and epilepsy, which implies “that not only are PWE at greater risk of developing psychiatric comorbidities, but also patients with primary psychiatric disorders are at greater risk of developing epilepsy” (Kanner, 2016, p. 307).

Not only are depression and anxiety particularly dominant in PWE, they also reach higher levels than in the general population (Angus-Leppan & Parsons, 2008; B. Green, Norman, & Reuber, 2017). Sixty per cent of PWE involved in a study in Zambia reported symptoms that indicate possible underlying depressive and/or anxiety disorders (Mbewe, Uys, & Birbeck,

2013). Suicide risk is also elevated in people with depression and comorbid anxiety (Kanner et al., 2012). Stress is regarded as a risk factor for the development of anxiety and depression, but for PWE it can also be a trigger for seizures (Lee, Lee, & No, 2010). PWE often mention that seizures are sometimes precipitated by stressful situations (Lee et al., 2010; Nakken et al., 2005). Attention deficit hyperactivity disorder (ADHD), bipolar disorder, movement disorder, pain disorders and sleep disorders are all mentioned as psychiatric comorbidities of epilepsy (Ottman et al., 2011). An American study found that bipolar disorder, ADHD and movement disorder “were more than twice as prevalent in people with versus without epilepsy” (Ottman et al., 2011, p. 314).

**2.6.1 Medical comorbidities.** A study conducted in the UK mentioned arthritis, diabetes, stroke, migraine, asthma, heart disease and fractures to be the most frequently stated medical comorbidities (Linehan, Tellez-Zenteno, Burneo, & Berg, 2011). In Africa, falls into an open fire was reported as the most common injury sustained as a result of epilepsy, while motor vehicle accidents and drowning are the most common in the UK (Angus-Leppan & Parsons, 2008). This indicates that such injuries vary according to geographic location. Premature death in PWE is reported to be approximately five times higher than in the general population in China (Mu et al., 2011), with deaths most often due to accidents (59%), drowning (45%), sudden unexpected death in epilepsy (14%) and status epilepticus (6.9%) (Mu et al., 2011).

## **2.7. Aetiology of Psychogenic Nonepileptic Seizures**

There is limited agreement on the psychological mechanisms underlying PNES, even though it is considered a mental health disorder (Brown & Reuber, 2016b). The specific contribution of various factors to the onset and maintenance of PNES varies from individual to individual. Some theorists focus more on the aetiology (the why) of the disorder than the mechanisms (how) of PNES (Baslet, 2011; Bodde et al., 2009; Brown & Reuber, 2016b). Contributing factors such as the role of traumatic experiences, family dysfunction, life stressors and other psychological factors are discussed next, followed by the various mechanisms for explaining how PNES may develop.

**2.7.1 Trauma.** Traumatic events such as childhood sexual abuse, adult sexual assault, emotional abuse, physical ill health and PTSD are comparatively common in patients suffering from PNES (Duncan, Oto, Martin, & Pelosi, 2006; Fiszman, Alves-Leon, Nunes, D’Andrea, & Figueira, 2004; Reuber, Howlett, Khan, & Grünwald, 2007). For instance, Fiszman et al. (2004) found very high rates of physical or sexual abuse (23–77%) and stated that 44 to 100 per cent of PNES patients reported incidences of general trauma. Furthermore, in many cases, health-related trauma was described as playing a major causative role in late-onset PNES (Asadi-Pooya & Emami, 2013; Duncan et al., 2006). In a study conducted by Reuber et al. (2007), a 90 per cent incidence of trauma is reported in PNES patients compared to others with neurological

symptoms. However, Brown and Reuber (2016a) argue that although there seems to be consistent support for a connection between exposure to traumatic events and the development of PNES, additional research is needed to confirm this premise.

**2.7.2 Family dysfunction.** Disorganized family settings pose several risks in the development and maintenance of PNES, such as disruptive patterns of functioning, communication, conflict, effective involvement and role definition (Krawetz et al., 2001). Additionally, Salmon, Al-Marzooqi, Baker, and Reilly (2003) report lower emotional expressiveness, more control over behaviour and over-protection in the childhood families of adult PNES patients. In a study conducted by Reuber et al. (2007), family discord and dysfunction are identified as perpetuating factors in over 50 per cent of patients suffering from PNES. Similarly, LaFrance Jr. et al. (2011) found that general family functioning presented in the unhealthy range for both PNES and ES patients and that criticism, distress and health problems were more prevalent. Given the importance of the interpersonal environment of the PNES patient, both in child-hood and adulthood, consideration should be given to the family system during the treatment and assessment of PNES (Hempel, Doss, & Adams, 2010; LaFrance Jr. et al., 2011).

**2.7.3 Life stressors.** The coping abilities of PNES patients are often challenged by acute and chronic stressors (Hempel et al., 2010). As an example, bereavement was identified as one of the salient features in the history of PNES patients as reported by nearly two-thirds of participants in a study conducted by Reuber et al. (2007). Furthermore, paediatric patients displayed a high incidence of peer relationship difficulties and academic or attentional difficulties, although other factors such as divorce, illness and bullying should not be discounted in these patients (Hempel et al., 2010). In fact, younger PNES patients were more likely to report stressful life events before the onset of PNES symptoms (Driver-Dunckley, Stonnington, Locke, & Noe, 2011). According to Brown and Reuber (2016b), research remains inconclusive in demonstrating whether PNES is triggered by stressful life events due to limited studies, methodological problems and low power.

**2.7.4 Personality.** Personality pathology in PNES patients is described as quite common and relevant to the outcome (Alsaadi & Shahrour, 2014; D'Alessio et al., 2006; Direk, Kulaksizoglu, Alpay, & Gurses, 2012; Reuber, Pukrop, Bauer, Derfuss, & Elger, 2004). In a study that used semi-structured psychiatric interviews based on the Structured Clinical Interview in the DSM-III-R and DSM-IV-R, it was found that 74 per cent of PNES patients had personality disorders, which was significantly higher than ES patients and healthy controls (Direk et al., 2012). Compared to ES patients and healthy controls, PNES patients were also found to present with personality profiles similar to borderline personality disorder (50.6%), characteristics of overly controlled personality (43.53%) and avoidant personality disorder (4.71%) (Reuber et al.,

2004). Similarly, D'Alessio et al. (2006) report a 33 per cent prevalence of borderline personality disorder in PNES patients, compared to 21 per cent in mixed PNES/ES patients. An interesting factor mentioned in the literature is the role of attachment trauma as a significant interpersonal and psychodynamic antecedent for PNES (Brown & Reuber, 2016a). This relationship between somatization and insecure attachment was explored in a study conducted by Quinn, Schofield, and Middleton (2008). The theory proposes that attachment trauma can contribute to individual levels of somatization (Fizman et al., 2004; Quinn et al., 2008; Reuber et al., 2007). It is evident from this description of the heterogeneity of the PNES population that the assessment and treatment of PNES patients require an integrated approach (Mökleby et al., 2002).

**2.7.5 Psychiatric comorbidity.** PNES occurs together with several psychiatric conditions with depressive, anxiety and personality disorders being the most recurrent (Fizman & Kanner, 2010; Kanner et al., 2012). It is then not surprising that PNES patients report considerably higher levels of anger, depression, hostility and anxiety than healthy controls (Mökleby et al., 2002). A study conducted by Cragar, Berry, Schmitt and Fakhoury (2005) agrees with these findings and indicates that PNES patients scored significantly higher in the domains of neuroticism, hostility, depression and anxiety than epilepsy patients. Other common comorbid disorders include post-traumatic stress disorder (PTSD), dissociative disorders and affective disorders (D'Alessio et al., 2006; Reuber, 2008). In fact, Fizman et al. (2004) provided evidence that PTSD occurs more frequently in patients with PNES than in ES patients or general population groups in a review of 11 studies that noted PTSD in 14 to 100 per cent of PNES subjects. Regarding paediatric patients, Hempel (as cited in Hempel et al., 2010, p. 179) states that "38% of paediatric patients with conversion disorders displayed a comorbid psychological condition, 36% experienced school problems." In summary, it is clear that comorbidities, personality profiles, family dynamics and trauma combine to form a highly diverse group that makes up PNES patients (Brown & Reuber, 2016b).

## **2.8. Mechanisms in the development of PNES**

It is crucial to recognize the complex interactions of psychosocial and environmental factors to understand the pathogenesis and the subsequent treatment protocols of PNES (Baslet, 2011; Kanner et al., 2012; LaFrance Jr. & Devinsky, 2004). Likewise, Brown and Reuber (2016b) reiterate that it is necessary to identify the mechanisms through which predisposing, precipitating and perpetuating factors contribute towards the development of PNES. Existing models that explore *how* PNES develops include that of Brown and Reuber (2016b, pp. 56–57). They offer the following descriptions: "PNES as the activation of dissociated material," where they postulate that mental functions are separated from consciousness as a result of a collapse in psychological integration; "PNES as hardwired responses" with the central premise that PNES is the product of pre-wired behavioural tendencies in the face of threats to the organism (Baslet,

2011); “PNES as a physical manifestation of emotional distress,” characterized by the tendency to express distress or avoidance of emotions by producing somatic symptoms (Cronje & Pretorius, 2013; Reuber, House, Pukrop, Bauer, & Elger, 2003); and “PNES as learned behaviour,” where PNES is typically seen as learned behaviour that is maintained by positive and negative reinforcement or intrinsic/extrinsic benefit.

Brown and Reuber (2016b) maintain that although there is credible evidence for each of the models, a universal account of the explanation of the disorder is still lacking. Towards this end, Brown and Reuber (2016b) use the integrative cognitive model of medically unexplained symptoms to create a framework with which to explain the pathogenesis of PNES (see Figure 2.3). In short, this model proposes that PNES manifests as a result of the triggering of the ‘seizure scaffold’, which is cognitive-emotional-behavioural action programmes that combine the consequences of learning and experience with inherent schemas (such as how to react to threats) (Brown & Reuber, 2016b). This, coupled with an ‘inhibitory processing dysfunction’ that is caused by chronic stress, arousal and other factors, is sufficient to produce an attack even in the absence of hyper- and hypo-arousal states (Brown & Reuber, 2016b). According to this model, predisposing, precipitating and perpetuating factors may or may not cause vulnerability, although these factors are not necessarily required for the process to take place (Brown & Reuber, 2016b).

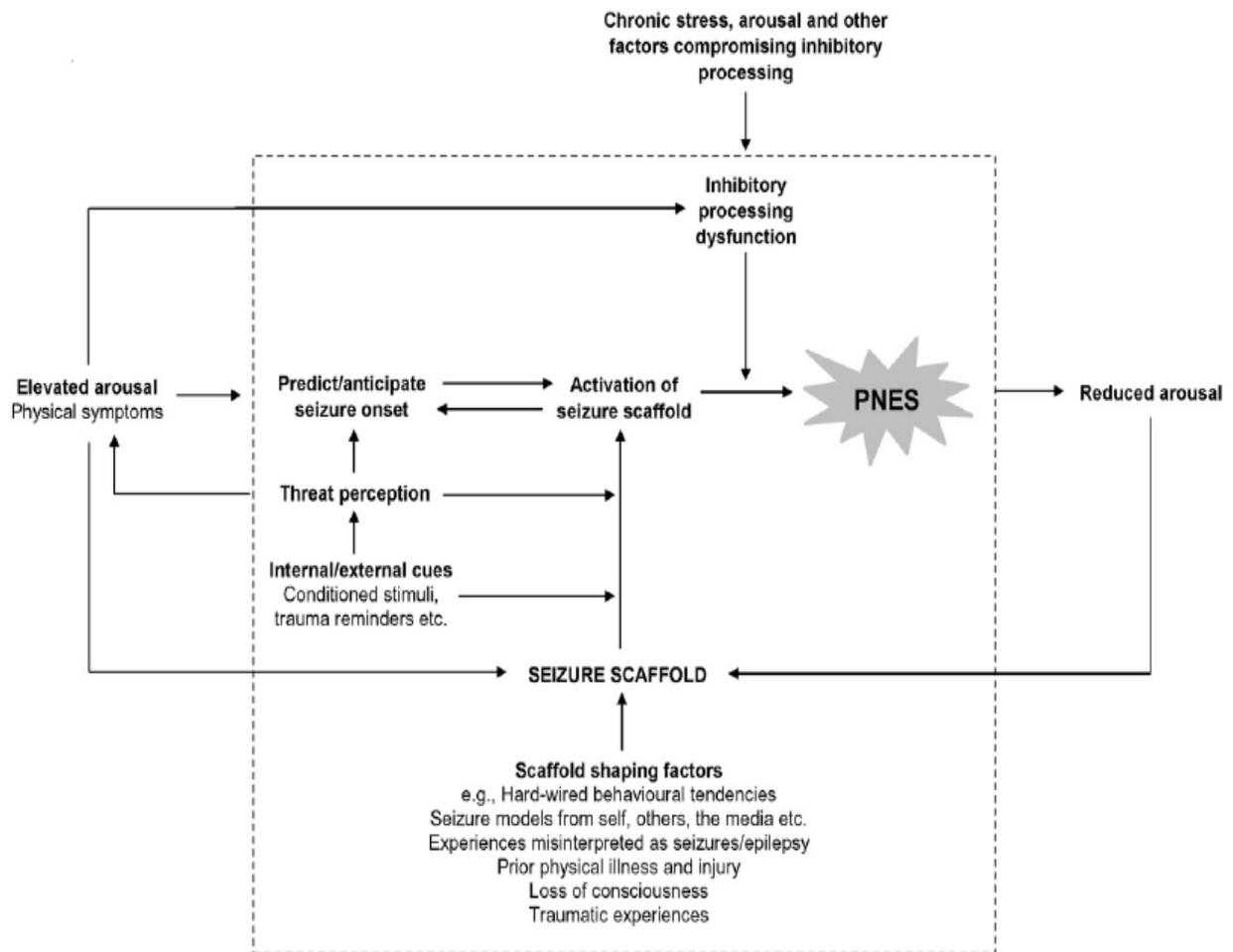


Figure 2.3. Hypothesized sequence of events in PNES. Reprinted from *Clinical Psychology Review*, Volume 47, R J Brown and M Reuber, *Towards an integrative theory of psychogenic non-epileptic seizures (PNES)*, pp. 55-70, 2016, with permission from Elsevier (see Appendix A3).

The framework described above is in keeping with the effectiveness of cognitive-behavioural therapy (CBT) approaches in treating PNES, although Brown and Reuber (2016b) advise that other psychotherapeutic treatment options may also be relevant in addressing issues such as emotional regulation, seizure triggers, interpersonal patterns of behaviour and traumatic memories.

## 2.9. Diagnostic Techniques

The lack of specialized diagnostic equipment in resource-poor countries implies that the diagnosis of seizures is fundamentally a clinical judgement by primary and secondary care HCPs with little or no specialized training in epilepsy management (Chin, 2012; Kvalsund & Birbeck, 2012; Radhakrishnan, 2009).

Medical practitioners often have to rely on the accounts of the patients and witnesses to diagnose epilepsy as they seldom have the opportunity to witness a seizure, making accurate diagnosis difficult (Institute of Medicine, 2012). In addition, there are several medical conditions that may look like seizures, such as PNES and NEEs. This makes diagnosis even more complicated (Institute of Medicine, 2012). An EEG or vEEG recording of semiological activity in the brain has become the gold standard for diagnosing seizures (Dixit, Banerjee, Chandra, & Tripathi, 2017). EEGs track and records brainwaves to detect abnormalities in electrical activity, which registers as asynchronous patterns indicative of seizure activity (Holtz, 2011). However, the accuracy of EEG has been questioned because of the possibility of over-interpretation of the EEG results, leading to ES misdiagnosis (Benbadis & Lin, 2008).

The current recommendation is that people who present with a first seizure undergo a full neurodiagnostic evaluation including an EEG recording, a CT scan of the head and MRI scan (Institute of Medicine, 2012; Krumholz et al., 2007). A full physical and neurologic examination and an investigation of the patient's medical history accompany the neurodiagnostic evaluation (Krumholz et al., 2007). Laboratory testing of blood glucose, blood counts and electrolyte panels may sometimes be helpful, although there is insufficient data to support its necessity in the diagnosis of seizures (Krumholz et al., 2007). However, developing countries often lack specialized equipment such as EEG, CT and MRI scans, leaving medical practitioners with physical examination and clinical history as the only diagnostic modalities available (Kvalsund & Birbeck, 2012). According to the WHO, Namibia has 4.78 CT units, 0.87 MRI units and 0.77 EEG monitors per million people, making this country no exception (World Health Organization, 2016). However, an interesting study conducted in India reported that mobile phone images could be successfully harnessed to classify seizures accurately (Dash et al., 2016). This finding may have benefits for a developing country such as Namibia where mobile phones are readily available.

Differentiating between ES and PNES can be clinically challenging, and the average period to establish a definitive diagnosis of PNES is reported as 7.2 years (Reuber et al., 2002). A study that was part of an ILAE Commission on Neuropsychobiology Non-Epileptic Seizures Task Force initiative, reported that not all countries have access to vEEG, which is the gold standard for making a definitive PNES diagnosis (Benbadis, 2005; LaFrance Jr., Baker, et al., 2013). As an alternative, the authors outline a staged approach to diagnose PNES by evaluating key diagnostic methodologies that include conversation analysis, the patient's history, hypnosis, neuroimaging, neurophysiologic, neurohumoral and neuropsychological testing, as well as EEG, ambulatory EEG and vEEG-monitoring (LaFrance Jr., Baker, et al., 2013). The alternatives described allow developing countries with lower and middle income population groups, such as Namibia, the opportunity to diagnose PNES in the absence of vEEG-monitoring (LaFrance Jr.,

Baker, et al., 2013). However, before any formal diagnostic techniques can be employed, a thorough history of the events has to be recorded and open, non-suggestive questions should be used where possible to allow several alternatives for the events to be explored (Kellinghaus & Modell, 2010).

**2.9.1 EEG.** Electroencephalography is used to track and record brainwaves to detect abnormalities in electrical activity, which registers as asynchronous patterns indicative of seizure activity (Holtz, 2011). A simultaneous video recording of the clinical manifestations of events is combined with EEG results in a vEEG diagnosis (Benbadis & LaFrance Jr., 2010). The aim of vEEG-monitoring is to demonstrate the absence of any asynchronous patterns or consistencies with known seizure types in order to differentiate between ES and PNES (Benbadis & LaFrance Jr., 2010; LaFrance Jr., Baker, et al., 2013; Perez & LaFrance Jr., 2016). The diagnosis of PNES can therefore be made with confidence when the event is recorded. The semiological assessment is matched with the EEG results and combined with an in-depth psychiatric and neurological history (Benbadis & LaFrance Jr., 2010). It is possible to misdiagnose seizures when the diagnosis is based on a singular event and when the history of the patient is not taken into consideration (B. J. Smith, 2014). However, there are limitations to EEG-monitoring, for example, EEGs are often misused and misread due to a lack of training and inexperience in the interpretation of results (Benbadis, 2007). Another significant concern is the interpretation of EEG findings out of clinical context or its over-interpretation with respect to clinical information (Benbadis, 2007). Further complications in the use of vEEG is that between 5 and 40 per cent of PNES patients have either simultaneous or a history of ES (Iriarte, Parra, Urrestarazu, & Kuyk, 2003). Ultimately, the lack of vEEG equipment and the time needed to perform adequate monitoring by using this equipment may be one of the biggest challenges for developing countries (Chemmanam et al., 2009).

**2.9.2 Provocation Techniques.** Arguably the biggest controversy and the core of much ethical debate in the diagnosis of seizures centres on the use of provocation techniques to induce an event during EEG testing (Benbadis, 2009; Iriarte et al., 2003; Leeman, 2009; Whitaker, 2001). These techniques are also called ‘activation procedures’ or ‘inductions’ and include hyperventilation, suggestion, photic stimulation and IV saline injection (Benbadis et al., 2000). Although proponents of provocative techniques maintain that these procedures are used in the best interest of the patient and have little potential for harm, it is argued that permanent damage is done to the patient-physician relationship through the use of deception (Leeman, 2009). Ethical considerations on the side of the patient are waged against the benefits of reaching a definitive diagnosis during inconclusive evaluations (Benbadis, 2009; Kanner, Benbadis, & Leeman, 2009; Leeman, 2009). According to Benbadis (2009), the consequences of not obtaining a definitive diagnosis include continued exposure to the adverse effects of antiepileptic

drugs, delays in proper therapy for coexisting psychiatric disorders, which ultimately leads to poorer prognosis. The effectiveness of using provocative techniques is illustrated in a study conducted by Benbadis et al. (2000) in which 84 per cent of inductions was successful in producing an event. This was supported by a study carried out by Hoepner et al. (2013) in which the PNES seizure rate was significantly increased by the provision of explicit information about the use of provocation techniques in seizure activation. In conclusion, Benbadis (2009) warns that although provocation techniques can be useful, they also have limitations. They should only be applied in proper clinical contexts by knowledgeable physicians when needed and should be discussed openly and honestly after the fact.

**2.9.3 Conversation Analysis.** It is postulated that examination of the close interactional and linguistic phenomena between physician and patient can provide a means of differentiating between ES and PNES (Cornaggia et al., 2012; Plug, Sharrack, & Reuber, 2009; Reuber, Monzoni, Sharrack, & Plug, 2009). For example, studies demonstrate that not only *what* patients say about a seizure, but more importantly, *how* they talk about their seizures can play a role in the differential diagnosis of PNES and ES (LaFrance Jr., Baker, et al., 2013; Reuber & Mayor, 2012). A study conducted by Plug et al. (2009) demonstrates accurate classification of seizures based on preferred metaphoric conceptualizations in 86 per cent of cases. Using a blind, prospective multi-rater study, Reuber et al. (2009) used two linguists to predict the medical diagnosis of seizures on the basis of video recordings and transcripts and reported an 85 per cent success rate. In another study conducted in Italy, a linguist was able to identify PNES or ES correctly in nine cases out of ten by using conversation analysis alone (Cornaggia et al., 2012). In the studies described above, there were marked differences in how ES and PNES patients used labels and foreign concepts. For example, PNES patients more often use metaphors of space or place, compared to ES patients who use metaphors depicting seizures as an agent or force (Plug et al., 2009). It is evident that the observation of patients' communication patterns with physicians has differential diagnostic potential and may be useful in the absence or as an adjunct to vEEG-recordings.

**2.9.4 Neurophysiology.** The use of postictal laboratory tests prove to be of little value in distinguishing between PNES and ES compared to vEEG due to its lack of sensitivity and specificity (LaFrance Jr., Leaver, Stopa, Papandonatos, & Blum, 2010; Willert, Spitzer, Kusserow, & Runge, 2004). Prospective measurement of serum neuron-specific enolase, creatine kinase and prolactin during vEEG-monitoring demonstrated limited discriminative power and the researchers concluded that it is not a definitive diagnostic tool for PNES (Willert et al., 2004). In another study conducted by LaFrance Jr. et al. (2010), assessment of brain-derived neurotrophic factor (BDNF) levels indicated lower levels in both PNES and ES patients

compared to healthy controls. It is therefore unlikely to be of use in discriminating between the two.

**2.9.5 Neuropsychological testing.** Some reviews illustrate that neuropsychological evaluation can help to distinguish between patients with PNES and ES (Ali et al., 2010; Azar et al., 2010; Hill & Gale, 2011). Azar et al. (2010) used a structured witness questionnaire to interview the ‘best’ witness on the ictal and postictal features of the patient. This questionnaire accurately predicted PNES or ES in 84.4 per cent of cases. In a study carried out by Ali et al. (2010), an instrument called the Ictal Consciousness Inventory (ICI) revealed that patients with PNES experienced more intense subjective experiences and higher levels of awareness during events than patients with ES. Finally, Hill and Gale (2011) demonstrated that the utility of self-reported clinical variables and semiological features combined with the Personality Assessment Inventory Conversion Subscale enabled them to correctly classify 84 per cent of all cases. However, Cragar, Berry, Fakhoury, Cibula, and Schmitt (2006) found no clinically useful differences between ES and PNES patients on four different measures of cognitive effort. Benbadis and La France Jr., (2010, p. 45) state that “neuropsychological evaluation is of little value in establishing the diagnosis of PNES.” However, this situation seems to be changing according to the more recent literature discussed here.

## **2.10. Treatment for Epileptic Seizures**

Gaps in knowledge, treatment, diagnosis, education, advocacy, legislation and research have kept PWE from leading productive lives, as “epilepsy is a multifaceted disease that needs a comprehensive approach” (Moshé et al., 2015, p. 894). Moshé et al. (2015) continue to explain that this knowledge gap among healthcare professionals arise due to their poor understanding of the multifaceted components of epilepsy and its implications. Multimodal strategies that address stigma, psychoeducation, advocacy of social and economic decision-makers and the promotion of empowerment are needed to better the lives of PWE (Birbeck, Chomba, Atadzhanov, Mbewe, & Haworth, 2007).

It is evident from the above literature that epilepsy has severe and debilitating effects on all aspects of a person’s life beyond the immediate impact of the seizures itself. Treatment and intervention programmes for epilepsy should therefore be tailored to the specific needs and experiences of the individual PWE.

**2.10.1 Pharmacology.** ES is primarily treated by medication that aims to control seizure recurrence (Ba-Diop et al., 2014; Institute of Medicine, 2012). A wide range of AEDs are available to treat seizures and these medications are often prescribed for people with epilepsy (Institute of Medicine, 2012). Approximately 70 per cent of PWE’s, seizures can be managed with AEDs, but unwanted adverse and toxic effects often lead to treatment failure and eventual

discontinuation (Perucca & Gilliam, 2012; S. P. Singh, Sankaraneni, & Antony, 2017). Headaches, fatigue, cognitive impairment, depression, irritability, double vision, agitation, aggressive behaviours, ataxia, fluctuations in weight and decreased bone mineral density count among the most common adverse effects of AEDs (Perucca & Gilliam, 2012). Patient education on the use of AEDs, regular clinical monitoring and preventative measures can minimize the adverse effects of AEDs (Perucca & Gilliam, 2012).

In developing countries, the majority of PWE do not receive AED treatment (Cameron et al., 2012; Mbuba, Ngugi, Newton, & Carter, 2008). The number of people who require treatment for ES but who are not receiving it is known as the treatment gap. In Africa this gap is estimated at approximately 75 per cent for low income countries and 90 per cent for the poorest (Kvalsund & Birbeck, 2012). Factors such as inadequate healthcare infrastructure, unskilled manpower, insufficient healthcare financing and unavailability of AEDs all contribute to the treatment gap (Cameron et al., 2012; Mbuba et al., 2008). Many PWE do not seek treatment due to long travel times to reach healthcare facilities and traditional and cultural beliefs regarding epilepsy (Mbuba et al., 2008).

**2.10.2 Surgery.** Some types of ES respond to surgery, which can be a potential treatment option for people whose seizures do not respond to medication (Institute of Medicine, 2012). “Surgical treatment includes resection, destruction, or disconnection of epileptic brain tissue” and depends on the localization of the epileptic zone (Moshé et al., 2015, p. 892). The success rate of surgery for certain types of ES range from 50 to 87 per cent (Chandra & Tripathi, 2010). However, more research is needed to assess the long-term results and effectiveness of surgery compared to other types of treatment (Institute of Medicine, 2012; Moshé et al., 2015; S. P. Singh et al., 2017). Due to the high cost, few neurosurgeons and paucity of sophisticated technology, ES surgery is rarely performed in resource-poor countries such as in SSA (Ba-Diop et al., 2014; Boling et al., 2009; A. Singh & Trevick, 2016).

**2.10.3 Vagal nerve stimulation.** People who suffer from severe epilepsies, who are not ideal candidates for surgery and who have failed multiple medications may be assisted by stimulating the vagus nerve (Institute of Medicine, 2012; Moshé et al., 2015; S. P. Singh et al., 2017). This type of deep brain stimulation entails the implantation of a device that is designed to prevent seizures through the electrical stimulation of the vagus nerve when abnormal electric activity is detected in the cortex (Moshé et al., 2015). This type of treatment is not widely available in SSA due to the cost (Caraballo & Fejerman, 2015).

**2.10.4 Psychotherapy.** Tang et al. (2014) claim that psychological therapies can play an integral part in the treatment of mental health disorders in PWE. Combination therapy in PWE has not been widely investigated, but it is suggested that psychotherapy can consolidate the efficacy of medication intervention (Kanner et al., 2012). In this context, a recent systematic

review found that “psychotherapy can improve depression and anxiety in patients with epilepsy” (Mehndiratta & Sajatovic, 2013, p. 39). Psycho-behavioural therapies generally aim to improve the individual’s ability to cope with epilepsy, but they may also increase psychological well-being and seizure control (Tang et al., 2014). Two systematic reviews of CBT for PWE suggest that this type of treatment may be effective for the treatment of depressive symptoms in epilepsy (Gandy, Sharpe, & Perry, 2013; Leeman-Markowski & Schachter, 2017). Trigger management as part of behavioural therapy aims to teach PWE “how to recognize or identify possible seizure triggers by observing environmental, personal, or lifestyle factors (such as lack of sleep, flashing lights, fever, or excessive alcohol consumption) that appear to increase their susceptibility to seizures” (Institute of Medicine, 2012, p. 171). Programmes that focus on social adjustment, improving quality of life, medication education and adjustment to seizures have shown promise (Mittan, 2009).

Several studies highlight the importance of programmes and interventions aimed at improving the coping abilities of PWE. These include the importance of exercise and diets, participation in sport, the self-management of epilepsy, psycho-education, the involvement of family in the management of epilepsy and programmes aimed at increasing epilepsy awareness and decreasing stigma (Bautista, 2017; Capovilla, Kaufman, Perucca, Moshé, & Arida, 2016; Elliott, Lu, Moore, McAuley, & Long, 2008; Mameniškienė, Guk, & Jatužis, 2017; Miller, Bakas, & Buelow, 2014; Njamnshi, Angwafor, Tabah, Jallon, & Muna, 2009; Ridsdale, Philpott, Krooupa, & Morgan, 2017).

### **2.11. Treatment for Psychogenic Nonepileptic Seizures**

Smith (2014) identifies two significant gaps regarding PNES research, namely the lack of definitive treatment options and the lack of effective referral practices in clinical care. It is therefore important to discuss the various treatment options and the specific considerations in the design of treatment plans in this section.

PNES is described as difficult to treat, with one of the main concerns being indecision regarding the most suitable treatment methods (O’Sullivan, Sweeney, & McNamara, 2006; Quinn, Schofield, & Middleton, 2010). It is unlikely that one specific therapeutic approach will be effective in all cases, and treatment plans should be tailored to target each person’s differing needs, personality and psychopathology profile (Brown & Reuber, 2016a; Reuber et al., 2004). Another researcher suggests that “[t]reatment options for PNES include psychotherapy, family counselling therapy, hypnotherapy, pharmacologic management, or combinations of these therapies” (Krebs, 2007, p. 26). Additionally, a multidisciplinary approach that combines psychological and neurological viewpoints and efforts to identify underlying causes of the disorder is paramount in tailoring treatment plans (Kanner, 2010; LaFrance Jr. & Devinsky, 2004). In a study conducted by Valente, Rzezak and LaFrance Jr. (2015), the most effective

treatment option was considered to be psychotherapy (92.2%), followed by education and psychopharmacology at 75 and 70.3 per cent respectively. Both psychodynamic and cognitive behaviour therapies are identified as possibilities for treating PNES (Brown & Trimble, 2000; LaFrance Jr. & Devinsky, 2004). However, the literature on the treatment of PNES is by no means conclusive, and several studies call for future controlled research to focus on treatment modalities (Brown & Trimble, 2000; LaFrance Jr., Reuber, et al., 2013; Quinn et al., 2010).

**2.11.1 Communicating the Diagnosis.** Presentation of the diagnosis is the first crucial step towards engaging the patient in treatment (Baslet, 2012; Kanner, 2010). Commitment to treatment is essential for recovery. However, PNES patients show low retention rates and therefore, “this ‘first therapeutic step’ is a decisive moment that may define the patient’s clinical and functional outcome, and hence it should be handled carefully” (Baslet, 2012, p. 588). Two other studies found that recovery was supported by acceptance and belief in the diagnosis (Shorvon & Luciano, 2007; Silva et al., 2001). Therefore, both the manner and the terminology used in communicating the diagnosis to the patient plays a major role in patients’ reaction to the diagnosis and the ramifications of the disorder (Farias, Thieman, & Alsaadi, 2003; Stone et al., 2003). It is evident from the literature that factors such as the confidence with which the diagnosis is made, the attitude of the doctor and the explanation used to describe the diagnosis all play a role in the patient’s reaction (Mellers, 2005). It is important that the physician gains the patient’s trust by making it explicit that he or she believes that the patient’s attacks are genuine and not volitionally produced (Brown & Trimble, 2000; Karterud, Knizek, & Nakken, 2010). Therefore, allowing sufficient time to communicating the diagnosis and showing respect for the patient’s perceptions are both considered to be of paramount importance for the delivery of the diagnosis (Karterud et al., 2010).

Surprisingly, some studies show that seizure frequency can be reduced by simply providing patients with a diagnosis of PNES (Farias et al., 2003; Mayor et al., 2012). In a study conducted by Farias et al. (2003), two-thirds of the sample ceased to have any more seizures after a definitive diagnosis was communicated, whereas in a survey carried out by Mayor et al. (2012), one-sixth of patients reported a cessation in seizures for a six-month period, where after it resumed again. Therefore, in an attempt to facilitate the communication of a PNES diagnosis, Hall-Patch et al. (2010) and Mellers (2005) describe procedures such as the use of an information booklet and communication strategy that can be used to communicate the diagnosis to the patient successfully. In fact, the same study showed a drastic reduction or event freedom in 14 per cent of the 50 newly diagnosed PNES subjects at two weeks, and a further 20 per cent reduction at eleven weeks after delivery of the diagnosis (Hall-Patch et al., 2010). Therefore, once the diagnosis had been effectively delivered to the patient, the next step would be to

identify suitable psychotherapeutic techniques that can be used in the treatment of the disorder. Different treatment options are discussed briefly in the next section.

**2.11.2 Cognitive Behavioural Therapy.** CBT is a short-term, goal-oriented psychotherapeutic intervention that focuses on modifying underlying patterns of thought and behaviour related to dysfunctional views of reality that presents as psychopathological symptoms (LaFrance Jr. & Barry, 2005). Baslet (2012, p. 589) heralds CBT as the “psychotherapeutic treatment with the highest level of efficacy evidence.” This is due to a pilot randomized, controlled trial performed by Goldstein et al. (2010) in which PNES event frequency decreased significantly after receiving CBT treatment for a period of four months, compared to receiving only standard medical care. In a similar study conducted by LaFrance Jr. et al. (2014), seizure frequency was reduced by 51.4 per cent in patients receiving CBT compared to subjects receiving only sertraline or standard medical care. The efficacy of CBT in the treatment of PNES was also evident in a study conducted by Kuyk, Siffels, Bakvis, and Swinkels (2008), which reported a seizure reduction of over 50 per cent in 81 per cent of patients who received treatment based on cognitive-behavioural principles. In conclusion, CBT may be a cost-effective, time-limited intervention that can be successfully applied in not only the treatment of PNES, but also to improve psychosocial functioning and comorbid psychiatric symptoms (LaFrance Jr. et al., 2009).

**2.11.3 Psychodynamic Therapy.** Psychodynamic theory holds that childhood experiences play a major role in the development of maladaptive behavioural patterns that manifest as external symptoms of internal processes (LaFrance Jr. & Barry, 2005). According to this model, dissociation can therefore be viewed as a defence mechanism utilized in an attempt to protect the self from inconsistent traumatic memories (LaFrance Jr. & Barry, 2005). The goal of psychodynamic therapy is to facilitate awareness of maladaptive patterns in order to bring about change (Baslet, 2012). In a study conducted by Mayor, Howlett, Grünwald, and Reuber (2010) using brief augmented psychodynamic psychotherapy, 26 per cent of subjects reported freedom from seizures after treatment with a further 40 per cent of subjects reporting a 50 per cent reduction in seizure frequency. When comparing PNES treatment trials using CBT-based treatment with psychodynamic therapy, it is worth noting that the average intervention period for CBT (12 weeks) seems significantly shorter than that of psychodynamic interventions (20 to 32 weeks) (Baslet, 2012). Considering that psychodynamic therapy might not be as cost-effective as CBT-based interventions given the above information, it would still appear that psychodynamic oriented therapy might be useful in addressing the underlying psychopathology of PNES (LaFrance Jr. & Barry, 2005).

**2.11.4 Hypnotherapy.** Hypnosis has been identified as a helpful tool to assist in the diagnosis of PNES, although its usefulness in the treatment of PNES has not yet been proven due

to the lack of randomized controlled studies aimed at hypnosis and PNES (Baslet, 2011; Moene & Kuyk, 2010). Moene, Spinhoven, Hoogduin, and van Dyck (2002) examined hypnotherapy in relation to conversion disorder and concluded that hypnosis did not affect the outcome and, therefore, did not offer an effective form of treatment for conversion disorders.

**2.11.5 Group Psychotherapy.** The benefit of group therapies, irrespective of orientation, has shown promise in the treatment of PNES (Bullock, 2010). Some studies conducted on the effectiveness of group therapy focused on psychoeducation, while others used a psychodynamic format. For example, Zaroff, Myers, Barr, Luciano and Devinsky (2004) conducted a group intervention using psychoeducation. The results showed a minor decrease in PNES frequency, but more noticeable decreases in dissociative and post-traumatic symptoms and improvements in quality of life. These results appear similar to a study conducted by Chen et al. (2014), who concluded that their group psychoeducational intervention was associated with improvements in important areas of functioning, although attack frequency did not show any significant changes. An eclectic approach that combined behavioural and psychoanalytic techniques with psychoeducation proved to be useful in reducing seizure frequency, although it was suggested that individual therapies should be applied in treating comorbidity and traumatic events (Metin et al., 2013). In summary, the role of group therapy as an adjunct to individual therapy may have specific advantages such as decreasing social isolation, support network building and identifying possible causation by directly experiencing PNES in others (LaFrance Jr. & Barry, 2005).

**2.11.6 Family Therapy.** Given the prominence of family dysfunction as a possible risk factor in the development of PNES, one would expect that family therapy as a treatment modality for PNES would have received much attention. However, this does not seem to be the case. Family participation in the treatment of PNES patients receives anecdotal support in the literature (Krawetz et al., 2001; Reuber & House, 2002). However, Krawetz et al. (2001) provide support for family involvement with the particular aim of addressing conflict and developing verbal communication skills.

**2.11.7 Pharmacology.** In an attempt to stop seizures in PNES patients, much harm is done by employing aggressive therapies and inappropriate treatments such as the use of AEDs (LaFrance Jr. & Blumer, 2010). In fact, most PNES patients receive unnecessary AEDs even though extensive observational data suggest that such treatment is ineffective or may even worsen PNES symptoms (LaFrance Jr. & Blumer, 2010; Reuber et al., 2002). What is more, 41 per cent of patients were found to still use AEDs a mean of four years after receiving the diagnosis of PNES (R. Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). Theoretical conceptualizations of PNES focus on depression as a significant aetiological factor, and given the frequency of anxiety and depression in PNES, pharmacotherapy is considered to be a

potentially useful intervention in its treatment (LaFrance Jr. & Blumer, 2010). In another study conducted by LaFrance Jr. and Blumer (2010), a 45 per cent reduction in PNES seizure rates were observed when comorbid depression was treated with sertraline. Similarly, seizures decreased by over 50 per cent and depression and anxiety scores improved in patients treated with venlafaxine (Pintor et al., 2010). Pharmacological management will customarily begin with tapering and discontinuing AEDs in patients with only PNES and introducing pharmacological agents to treat psychotic, anxiety and mood disorders (LaFrance Jr. & Blumer, 2010). Medication can therefore be an adjunctive measure to other treatment options in an attempt to provide a holistic patient treatment approach (LaFrance Jr. & Blumer, 2010).

**2.11.8 Multidisciplinary Approach.** Due to the heterogeneity of the PNES population, the severity of comorbid psychiatric disorders and the underlying psychosocial mechanisms, the evaluation and management of PNES patients require a multidisciplinary approach (Kanner, 2010). Studies exploring the viability of a multidisciplinary approach in the treatment of PNES delivered promising results. For example, in a programme that used a multidisciplinary approach based on cognitive-behavioural principles, a seizure reduction rate of over 50 per cent was found in 81 per cent of PNES patients, with a concomitant normalization of dissociation, anxiety and depression (Kuyk et al., 2008). The programme included prolonged inpatient admission and “treatment aimed at cognitive restructuring, trauma treatment, stimulus differentiation, coping skills training, behavioural analysis, and rational emotive therapy” (Baslet, 2012, p. 592). In another comprehensive inpatient programme consisting of physiotherapy, group therapy and hypnosis, 65.1 per cent of patients with a conversion disorder of a motor type, reported substantial improvement after treatment. However, hypnosis had no effect on outcome (Moene et al., 2002).

Due to the complexity of this disorder, it is vital that various HCPs contribute to the diagnosis and management of PNES. Therefore, the psychiatric management of PNES patients requires a team approach that includes neurologists, psychiatrists, psychologists, physiotherapists and social workers (Kanner, 2010).

## **2.12. Prognostic Factors in Seizures**

Traditionally, outcome measures for ES and PNES are based on seizure remission or frequency (Reuber, Mitchell, Howlett, & Elger, 2005). Although seizure control is important, it does not necessarily equate to enhanced social outcomes in either of the disorders (Camfield & Camfield, 2014; Jones et al., 2010). However, long-term outcomes seem to be worse for people with PNES than for PWE (Reuber et al., 2005). Even when people with PNES become seizure free, nearly half remain unproductive and continue to display signs of psychopathology (Jones et al., 2010; Reuber et al., 2005). In addition, people with PNES often develop psychosomatic

symptoms, such as fatigue or chronic pain, once the psychogenic seizures have stopped (Jones et al., 2010).

Although the outcome in PNES is seen as poor, a 1 to 10-year follow-up study with 164 patients proved that this result could also be variable (Reuber, Pukrop, Bauer, et al., 2003). This study reported that 71 per cent of patients continued to have seizures, 41 per cent were employed or attending school, 12 per cent were unemployed, 41 per cent were retired for health reasons and five per cent were on pension (Reuber, Pukrop, Bauer, et al., 2003). Favourable factors identified in this study included less dramatic attacks, lower dissociation scores, fewer somatoform complaints, younger onset diagnosis and greater educational achievements (Reuber, Pukrop, Bauer, et al., 2003). Additionally, better prognosis depends on high motivation for recovery, supportive family structure, childhood and adolescent onset, recent onset of PNES, no desire to seek disability compensation, and at least normal intelligence with insight into the causes of the condition (Ettinger, Dhoon, Weisbrot, & Devinsky, 1999; LaFrance Jr. & Devinsky, 2004). Furthermore, the importance of caregiver beliefs is highlighted as an important factor in long-term outcomes in a study conducted by Duncan, Graham, and Oto (2014).

As a result of underlying psychological factors and comorbid psychiatric disorders, some PNES patients resist treatment, while others are more accepting. For example, in a study conducted by Reuber et al. (2004), it was found that personality profiles characterized by emotional dysregulation showed poorer prognoses than those with overly controlled behaviour. Poorer outcomes are also predicted by severe personality disorders, a socially disordered environment, continued sexual abuse or domestic violence, marital or family dysfunction, a history of psychiatric disorders with failed treatments, and those seeking disability compensation or secondary gain (Krebs, 2007). Similarly, patients that do not accept the PNES diagnosis or display signs of anger or confusion have a worse outcome (Carton, Thompson, & Duncan, 2003). Patients who accepted the PNES diagnosis were 2.85 times more likely to become seizure free than those who did not (Duncan, Graham, & Oto, 2014). Overall, adults show worse prognosis than children do, with only 40 per cent of adults reporting seizure remission (Durrant, Rickards, & Cavanna, 2011). In conclusion, successful outcomes were often hampered by limited therapeutic resources, chronic psychiatric difficulties and limited acceptance of the diagnosis (Baslet, 2012).

A study that investigated the outcome domains for ES found that desired outcomes not only related to seizure frequency, but also included seizure severity, quality of life, adverse events, cognitive function, support from others, the independence of PWE and depression and anxiety levels (Noble & Marson, 2016). A multitude of factors contribute to ES outcome, such as socioeconomic status, age at onset, gender, sociocultural structures, healthcare disparities, material conditions and behavioural and biological factors (M. Szaflarski, 2014). Although

approximately 20 per cent of PWE fail to respond to AED treatment, most PWE may achieve seizure remission with the help of AEDs (Shorvon & Luciano, 2007).

Livneh and colleagues (2001) identify four main spheres of psychosocial problems that are at play in the process of adapting to a diagnosis of epilepsy. These include “(a) anxiety and concerns about the unpredictability and lack of controllability associated with the diagnosis of epilepsy, (b) perceived stigma and discrimination associated with the diagnostic label of epilepsy, (c) increased impact of epilepsy-specific life stressors, and (d) health and functional consequences linked to denial of condition” (Livneh et al., 2001, p. 535). Personality type, cognitive abilities and environmental circumstances may all have an influence in how people cope with these psychosocial problems (Lazarus & Folkman, 1984). Coping strategies are traditionally classified as either problem-focused or emotion-focused. Problem-focused strategies would include individuals attempting to manage their condition actively through information seeking, planning and positive reframing. Emotion-focused strategies include avoidance and denial (Bautista, Rundle-Gonzalez, Awad, & Erwin, 2013; Livneh et al., 2001).

Generally, PWE favour problem-focused strategies such as religion, acceptance and emotional support over emotion-focused strategies such as humour, denial and substance abuse, as evidenced by the results of a study conducted in the USA (Bautista et al., 2013). Problem-focused coping was also associated with increased psycho-social outcomes and decreased levels of depression and anxiety in PWE (Livneh et al., 2001). The personality characteristic of locus of control mainly determines the type of coping strategy employed, whether problem- or emotion-focused (Quintas et al., 2012). An individual’s views regarding the amount of control they have over events in their lives can be either internal (outcomes are due to their own efforts) or external (consequences are the result of chance, luck or fate and they have little personal control over events) (Colman, 2006). A more passive stance and depressive type thinking is associated with an external locus of control, which is reported to be more prevalent in PWE than in the general population (Hermann & Jacoby, 2009). It is then not surprising that older adults with epilepsy describe the condition as a balancing act between loss of control, stigma, reliance on others and a desire for “strategies to restore loss of control, acceptance, increased awareness of epilepsy and supportive relationships” (Yennadiou & Wolverson, 2017, p. 87).

Several studies highlight the importance of programmes and interventions aimed at improving the coping abilities of PWE. These include the importance of exercise and diets, participation in sport, the self-management of epilepsy, psycho-education, the involvement of family in the management of epilepsy and programmes aimed at increasing epilepsy awareness and decreasing stigma (Bautista, 2017; Capovilla et al., 2016; Elliott et al., 2008; Mameniškienė et al., 2017; Miller et al., 2014; Njamnshi et al., 2009; Ridsdale et al., 2017).

### 2.13. Social Burden of Seizures

In the process of compiling the literature review, eighteen articles dated between 2005 and 2017 that included both epilepsy and stigma in the title, were identified (e.g., Amjad, Nasrabadi, & Navab, 2017; Atadzhanov, Haworth, Chomba, Mbewe, & Birbeck, 2010; de Boer, Mula, & Sander, 2008; Guo et al., 2012; Luna et al., 2017; Mohamed, Balla, Hussien, & Dafaalla, 2014; G. Smith et al., 2009). However, a similar search delivered no results for PNES. Although several articles make a passing reference to the stigma attached to PNES, it seems that it has not received the same attention in the literature as ES (Perez & LaFrance Jr., 2016; Robson & Lian, 2016). What is evident from the literature is that people with PNES report lower explicit self-esteem than PWE, and that this is associated with disability and perceived stigma (Dimaro et al., 2015). Taking into consideration that people with PNES often present with existing psychiatric comorbidities, personality disorders, family dysfunction and trauma (Brown & Reuber, 2016a; Mökleby et al., 2002), the social burden of seizures may be a result of these factors and not exclusively a result of the seizures alone. In addition, the use of ineffective coping strategies by people with PNES may contribute to the social burden of this disorder (Cronje & Pretorius, 2013). Bodde (2007) states that seizures have an impact on social functioning and occupational possibilities. Furthermore, in a study conducted by Krawetz et al. (2001, p. 41), it was found that people with PNES “experience comparable levels of employment, income, education, and quality of life compared to epileptic subjects.” However, other studies report that people with PNES often experience lower quality of life than PWE (B. Green et al., 2017; Karakis et al., 2014). Unemployment rates influence indirect cost, as a significant number of PNES patients are unemployed at the time of diagnosis due to possible discrimination, inability to drive a motor vehicle and workplace safety concerns (Hamilton, Martin, Stone, & Worley, 2010). In Germany, more than 50 per cent of patients with PNES received disability benefits up to 10 years post diagnosis (Reuber, Pukrop, Bauer, et al., 2003). Krawetz et al. (2001) reported similar results in Canada, where 55 per cent of patients were unemployed at the time of diagnosis.

The following discussion focuses on the social burden experienced by PWE and is based on a quote by Betts and Duffy (1993) as cited in Marchetti et al. (2008, p. 249), “PNES may lead to severe social and psychological impairments. Patients and their family members are subject to the same problems as people with epilepsy: stigmatization, poor schooling, unemployment, difficult interpersonal relationships, and social maladaptation.” Furthermore, professionals often misdiagnose PNES as ES (Baslet, Dworetzky, Perez, & Oser, 2015; LaFrance Jr., Baker, et al., 2013) and the two disorders may, therefore, also be perceived and treated as the same by lay people.

As early as 1975, the Commission for the Control of Epilepsy and its Consequences stated that “Possibly the least understood and most neglected aspects of epilepsy are the social, psychological, and behavioural problems that are so common... [These] can be more handicapping than the actual seizures, yet these problems often are unrecognized and little skilled assistance is available” (as cited in Mittan, 2009, p. 371). In the period 2010-2014, the number of articles published in a prominent epilepsy journal that include the terms “psychosocial”, “behavioural” and “psycho-behavioural” have increased 2.5-fold due to advances in the understanding of the psychosocial and behavioural comorbidities of epilepsy (J. Wagner, 2014). This seems to be a reflection of the increased awareness that psychological and social factors play an important role in the lives of PWE. Unfortunately, a limited number of these studies focus on epilepsy in an African context.

The Global Burden of Disease Study 2015 found that only HIV infection had greater disability weight than uncontrolled, severe epilepsy (GBD 2015 DALYs and HALE Collaborators, 2016). Additionally, it is reported that PWE “have significant neuropsychological, psychiatric, and social impairments that limit their education, employment opportunities, and possibilities for marriage” (Zhao et al., 2012, p. 369). The Global Burden of Disease Study 2015 confirms this by stating that life chances are reduced for adults with epilepsy in terms of marriage and employment and that they face devastating social consequences, such as premature mortality, stigma and discrimination (GBD 2015 DALYs and HALE Collaborators, 2016). For example, PWE in Zambia reported higher mean perceived stigma scores, less education and poorer employment status (Birbeck et al., 2007). One-quarter of respondents in a study conducted in Zimbabwe experienced problems with interpersonal relationships, difficulties with public transport when required to travel long distances and sexual functioning (Mielke, Sebit, & Adamolekun, 2000). PWE in Nigeria are commonly at risk for suicide. This risk was associated with emotional distress and poor seizure control (Nuhu, Lasisi, Yusuf, & Aremu, 2013). Epilepsy patients in rural Zambia reported functional difficulties in the domains of solving daily problems, the speed of thinking, relationships with co-workers, friends and family and using public transportation (Birbeck et al., 2007).

Studies on PWE in China and Vietnam describe epilepsy as enormously disruptive and report that affects family members as well as employment and marriage prospects (Jacoby et al., 2008). This was also confirmed in a study performed by Kobau et al. (2014), in which adults with epilepsy reported significantly worse psychological health, more cognitive impairment, difficulty in participating in some social activities and reduced health-related quality of life. The literature clearly reveals that living with epilepsy is challenging because of not only the constant uncertainty associated with seizures, but also comorbid mental illnesses, social disadvantage, stigma, cognitive dysfunction and limitations on daily activities (Institute of Medicine, 2012).

Misbeliefs often lead to stigma and hamper access to appropriate health care services and treatment for epilepsy (Tran et al., 2007). In Africa several cultures view epilepsy is often seen as a curse or the result of witchcraft or possession by evil spirits (Darghal, 2010; Mushi et al., 2011; Osungbade & Siyanbade, 2011). The resultant stigma from these erroneous beliefs leads to reduced opportunities for employment, marriage and education among PWE (Wilmshurst, Birbeck, & Newton, 2014). This may further lead to poverty, food insecurity, physical vulnerability and even physical and sexual abuse (Birbeck et al., 2007; Birbeck & Hesdorffer, 2011; Carter et al., 2012; Chomba, Haworth, Atadzhanov, Mbewe, & Birbeck, 2007).

In Ethiopia, there is a strong link between epilepsy and poverty, as epilepsy was associated with subsistence farming and lower educational achievement (Vaid et al., 2012). In Rwanda, respondents revealed many stigmatized beliefs, with 66 per cent indicating that PWE “should not be entitled to schooling, to work (72%), the use of public places (69%), or to marriage (66%)” (Sebera et al., 2015, p. 128). Fifty per cent of respondents in the same study believed that epilepsy was untreatable and 40 per cent indicated that it was a contagious disease (Sebera et al., 2015). Similar attitudes were reflected in a study conducted in Laos with widely shared beliefs that epilepsy is contagious (57%), fatal (60%), incurable (>75%) that they would not share a meal with a PWE (62.7%) or allow someone from the household to marry a PWE (61.4%) (Tran et al., 2007). In a study conducted in Cameroon, 35 per cent of respondents linked epilepsy to insanity. The respondents in this study also felt that women with epilepsy are unable to fulfil community expectations of marriage such as raising children and doing household chores (Njamnshi et al., 2009). In the same study 57.3 per cent of respondents discriminated against employment of PWE (Njamnshi et al., 2009).

Although very little research has been performed on seizures in Namibian, it is evident from the above literature that people with seizures face huge barriers in Africa and that interventions to decrease stigma and increase awareness about ES and PNES are greatly needed.

#### **2.14. Economic Burden of Seizures**

The socioeconomic burden of seizure disorders is considerable, especially in resource-poor countries (Anand, Siraz-UI, & Suresh, 2004; Hong et al., 2009; Mosser, Schmutzhard, & Winkler, 2007). The Institute of Medicine describes the cost burden of epilepsy in terms of “the direct costs of health and social services (e.g., costs related to physician visits, hospital use, seizure medications, counselling, rehabilitation, training) and the indirect costs related to lost productivity, reduced functioning, and early mortality” (2012, p. 208). Similarly, PNES causes direct and indirect costs by placing a heavy burden on emergency and nonemergency healthcare services, and on the economy as a whole (Ahmedani et al., 2013; Asadi-Pooya & Emami, 2013; Martin, Gilliam, Kilgore, Faught, & Kuzniecky, 1998). Cost factors include pre-diagnosis costs,

tertiary care, AED use, comorbid medical and psychiatric conditions and employment and financial assistance (Hamilton et al., 2010).

Taking into consideration that the average time to reach a definitive PNES diagnosis is 7.2 years, considerable costs are incurred over an extended period for a large number of tests, procedures and treatments (Reuber et al., 2002). Martin et al. (1998) reported a mean expenditure of USD 8156 per PNES patient before diagnosis, which decreased to USD 1 306 after PNES was diagnosed, an 84 per cent average reduction. Similarly, clinic visits declined by about 80 per cent, diagnostic procedures went from 55 to 14, emergency room visits dropped by 97 per cent, laboratory testing by 80 per cent, diagnostic testing by an average of 76 per cent and medication by 69 per cent (Martin et al., 1998). Although the economic impact of PNES in the USA had not been formally established at that time, it was estimated that “lifetime dollars costs per patient cohort year for a PNES group could range from USD 110 million to USD 920 million” (Martin et al., 1998, p. 385). Razvi, Mulhern, and Duncan (2012, p. 7), “performed a 1-year prospective audit of the use of a group of PNES-related health-care items in patients with newly diagnosed (mean duration: 7.3 months) PNES from PNES onset to diagnosis and from diagnosis to six months post diagnosis.” The authors reported a 94 per cent reduction in emergency department visits, a 100 per cent reduction in GP visits, a 100 per cent reduction in hospital admissions, and a 100 per cent reduction in EEGs. In another study, overall costs dropped from a mean of USD 4 567 in the 12-month period before PNES diagnosis to an average of USD 2 783 in the 12-months period after the diagnosis of PNES (Ahmedani et al., 2013). In addition, a study conducted on the long-term usage of healthcare services by 188 PNES patients, 5 to 10 years after diagnosis, reported reductions in healthcare utilization across several services (Duncan, Graham, Oto, et al., 2014). However, the same study indicated that only 22.8 per cent of participants were employed at the 5 to 10 years follow-up and that antidepressant usage increased from 23.9 to 39.5 per cent in the same period (Duncan, Graham, Oto, et al., 2014).

It is hard to estimate the overall economic burden of ES as it encompasses services across different settings of care and treatment approaches (Institute of Medicine, 2012). Costs associated with the management of ES fluctuate during the course of the disorder and depend on the type of ES involved, with direct costs reaching a peak during initial onset and diagnosis and decreasing as the seizures are controlled (Institute of Medicine, 2012). A study based on a retrospective review of cost-of-illness studies across 28 European countries found that the total cost per ES case ranged between €2,000 and €11,500 (Pugliatti, Beghi, Forsgren, Ekman, & Sobocki, 2007). Fifty-five per cent of the total epilepsy cost, which was €15.5 billion in 2004, related to indirect costs with direct costs making up 18 per cent (Pugliatti et al., 2007). Outpatient care dominated the healthcare costs at 47 per cent and AED treatment comprised 15 per cent at €400 million (Pugliatti et al., 2007). A similar cost-of-illness study conducted in

China stated that the mean annual cost for ES accounted for more than half the mean annual income of Chinese patients at a total of USD 773 per annum per patient (Hong et al., 2009). The authors reported a direct cost of USD 372 per year per patient, nonmedical direct costs of USD 111 and loss of productivity at USD 289 (Hong et al., 2009). In Tanzania it was found that hospital costs for ES alone ranged between USD 20.2 and USD 284.4 for a country where the national gross product per capita was reported as USD 280 in 2002 (Mosser et al., 2007). In South Africa it is estimated that the overall annual out-of-pocket cost for ES treatment at public health facilities amounts to USD 58.41 although transportation costs and waiting times contributed significantly to indirect costs of treatment (R. G. Wagner et al., 2016).

Even though very little is known about the overall impact of seizures in Namibia, it is quite clear from the literature that seizure diagnosis results in substantial cost for the healthcare infrastructure and the utilization of services to treat patients with seizures. This combined with the economic impact of unemployment and disability benefits further increases the financial burden with respect to seizure disorders.

It is evident from the literature discussed that much effort is expended on research regarding seizures from the perspective of the patient and specific challenges encountered in the diagnosis and treatment of these disorders. Although it is important to identify the factors that contribute to the development and maintenance of seizures, it is equally important to acknowledge the role of the service providers in providing care for this disorder (McMillan et al., 2014). However, few studies focus exclusively on evidence-based management pathways, information about health systems and the perceptions and frustrations encountered by HCPs in the management of specifically PNES (Mayor, Smith, & Reuber, 2011; Valente, Rzezak, & LaFrance Jr., 2015). The only studies that explored the existing healthcare infrastructure and strategic health practices used for PNES in specific countries were conducted in the USA, Chile, UK and Brazil (LaFrance Jr. et al., 2012; Mayor, Smith, & Reuber, 2011; Valente et al., 2015). Although studies on ES in developing countries are more readily available, no studies have been performed in Namibia (Kvalsund & Birbeck, 2012; Mbuba et al., 2012; R. G. Wagner et al., 2016). There is a need to explore the perceptions and experiences of people who render services to people with seizures in the context of current healthcare practices and infrastructure that may influence seizure care in a developing country such as Namibia.

### **2.15. Biomedical Healthcare Services**

A range of healthcare services are available to the Namibian population. The most important two include the formally recognized biomedical system and the informal traditional medical system. Biomedicine is also called Western medicine, conventional medicine, allopathic medicine, orthodox medicine and mainstream medicine (National Cancer Institute, 2013). Biomedical services in Namibia include private hospitals, pharmacies and doctors or

government-owned and -operated hospitals and clinics. In terms of the country's biomedical infrastructure, the two largest hospitals in the country are situated in Windhoek, the Katutura Intermediate Hospital and the Windhoek Central Hospital, both state-owned and -operated. The remainder of the country is served by smaller government-owned hospitals and clinics and some private hospitals. Total expenditures on health are covered by government in 60.4 per cent of cases while 18.65 per cent of the total health expenditure is covered by private health insurance and the remainder is out-of-pocket (World Health Organization, 2016). Namibia has 268 doctors and 66 specialists who are employed by government, three of which are psychiatrists. There are no neurologists in full-time government employ (Ministry of Health and Social Services, 2013). According to the WHO, Namibia has 0.374 physicians per 1 000 people, 12 psychiatric beds per 100 000 people, 4.78 computerized tomography (CT) units, 0.87 magnetic resonance imaging (MRI) units and 0.77 electroencephalography (EEG) monitors per million people (World Health Organization, 2016). No video-EEG (vEEG) monitors are available in the country. They are known as the gold standard for diagnosing PNES.

The understanding of symptoms within a biomedical framework is largely based on the explanatory model (EM) of illness according to Western culture (Kleinman, 1977). Today, most modern doctors are trained in biomedicine, the dominant model of disease (Bassett, 2011; Engel, 2012; Mizrachi, Shuval, & Gross, 2005). In biomedicine's understanding, "a disease's etiology, symptoms and signs, natural history, treatment and prognosis are considered to be similar across all individuals, ethnic groups or cultures" (Fabrega & Silver, 1973; Eisenberg, 1977; Kleinman, 1986 as cited in Yew & Noor, 2014, p. 114). It appears that this statement applies to scenarios where a clear biological component is involved in the disease. However, as soon as the focus moves to factors that cannot be readily explained by biological factors, it opens the floor for much debate and disagreement among HCPs, as is evident from the following discussion.

The ILAE defines ES as "a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain" (Fisher et al., 2014, p. 476). Although PNES resembles or mimics ES, it is in reality episodes of altered experience, sensation and movement, not as a result of abnormal electrical discharges in the brain, but rather underlying psychological stressors (Bodde et al., 2009; Reuber, Pukrop, Mitchell, et al., 2003; B. J. Smith, 2014). Conventionally, symptoms that arise as a result of organic pathology or physiological dysfunction (physical causes) are seen as 'medically explained symptoms' (MES) whereas symptoms that are unexplained by organic disease is referred to as 'medically unexplained symptoms' (MUS) (Carson, 2000; Hatcher & Arroll, 2008; Klaus et al., 2013). As can be seen from the above two definitions, ES would be categorized as MES as symptoms arise from identifiable physical causes, while PNES resorts under MUS due to the medically unexplained nature of its symptoms, which instead arise as a result of psychological (psychiatric)

causes. This distinction between MES and MUS for ES and PNES is also reflected in how the two conditions are customarily managed by HCPs. Treatment for MES seems relatively straightforward with pharmacology in the form of anti-epileptic drugs (AED) being the preferred choice of action in the case of ES (Ba-Diop et al., 2014; Institute of Medicine, 2012). The most preferred and effective treatment for MUS, such as PNES, is found in various forms of psychotherapy. However, the misdiagnosis of PNES as ES is common and often results in prolonged treatment with AEDs (Alsaadi & Marquez, 2005; Baslet, 2012; Baslet et al., 2015; Krebs, 2007; LaFrance Jr., Baker, et al., 2013). The likelihood of misdiagnosis is reflected in the confidence with which HCPs make a diagnosis of PNES, with neurologists expressing the most confidence in dealing with PNES patients (mean 7.71 on a scale of 0 to 10), followed by nurses (7.15) (Sahaya, Dholakia, Lardizabal, & Sahota, 2012). In addition, the opinions of GPs towards the clinical management of PNES patients were investigated in a study conducted by O'Sullivan et al. (2006). GPs regarded their mean confidence on PNES as 5.7 on a scale of 1 to 10, and although 35 per cent of GPs felt that psychiatric or psychological intervention is beneficial, 57 per cent did not feel comfortable to make the initial referral (O'Sullivan et al., 2006). Furthermore, the most efficient discipline to follow up PNES patients was regarded as the GP alone, 30 per cent, followed by GP and neurology, 22 per cent, and neurology and psychology or psychiatry, also 22 per cent (O'Sullivan et al., 2006). The problems are confounded by the perception that "physical disorders are seen as 'real' and patients are seen as victims, whereas psychiatric disorders are seen as 'not real', and patients are seen as partly responsible for their problem" (Hatcher & Arroll, 2008, p. 1124).

This perception is further reflected in the debate surrounding the controversial nature of conversion disorders, and although the psychiatric taxonomy recognizes its validity, many HCPs still consider it contrived and lacking organic cause (Abubakr, Kablinger, & Caldito, 2003; Sahaya et al., 2012). What is more, health professionals commonly misinterpret the psychogenic origin of these seizures as a sign of deliberate fabrication. They may then assume a negative attitude, causing reluctance in the patient to accept the diagnosis (Baslet, 2012). A study that investigated the illness perceptions of healthcare professionals, found that respondents believed PNES patients to have 'personal control' over their seizures (Worsely, Whitehead, Kandler, & Reuber, 2011). In a study conducted by Sahaya et al. (2012), nearly half of the nurses felt that PNES patients have voluntarily control over seizures and that it is 'fake.' This situation is further complicated by differences in beliefs among healthcare professionals themselves. For example, Whitehead and Reuber (2012) conducted a study comparing neurologists and psychiatrists' perceptions of PNES. Results showed that psychiatrists were more inclined to ascribe PNES to mainly physical causes, whereas neurologists supported psychological causes as determinants in PNES (Whitehead & Reuber, 2012). This is in line with Smith's (2014) viewpoint that PNES is

situated in the borderland between neurology and psychiatry, with neither being prepared to take ownership. Baslet (2012) reflects a similar sentiment and argues that PNES is treated like an ‘orphan’ disorder where neither psychologists nor psychiatrists want to treat it for fear of missing ES when the symptoms continue. A related scenario exists in the case of ES, where seizure freedom continues to be an important treatment goal for ES, notwithstanding growing evidence that the psychological and social domains have the greatest impact on the quality of life of PWE (Elliott & Richardson, 2014). Neurologists often disregard the psychosocial aspects of ES and instead focus only on the physical symptoms of the seizures (Blumer, 2008). Subsequently the author urges that “Psychiatrists must become familiar with the psychiatric aspects of epilepsy to be able to assist the neurologists who focus on the neural complexities of the illness” (Blumer, 2008, p. 216).

It is not surprising that patients themselves are more inclined to ascribe their symptoms to somatic causes (MES) even with evidence that their seizures are caused by underlying psychological factors (MUS) (Karterud et al., 2010). Some studies indicate clear differences between how doctors and patients perceive PNES (R. Thompson et al., 2009; Whitehead, Kandler, & Reuber, 2013). Neurologists regard PNES as a disorder related to psychological problems for which psychotherapy is the most suitable treatment (Whitehead & Reuber, 2012), whereas patients with PNES are more likely to consider their seizures as physiological rather than psychological (Robson & Lian, 2016; Stone, Binzer, & Sharpe, 2004). Thompson et al. (2009) confirm that there is a marked disparity between doctor and patient opinions regarding the cause of PNES symptoms in that patients perceive it to be exclusively physical, whereas doctors believe it to be a manifestation of mental illness or distress. “The perception of a fundamental difference in beliefs is likely to be one important reason why neurologists describe the process of communicating the diagnosis of NES as ‘negotiating a minefield’” (R. Thompson et al., 2009, p. 508). A study that compared the perceptions that patients and neurologists have of ES and PNES reports that patients attributed the same importance to psychological and non-psychological factors in the causation of the two disorders (Whitehead et al., 2013). Neurologists, however, attached more weight to the non-psychological causes of ES than did patients, who perceived the aetiology as wholly or partially psychological (Whitehead et al., 2013). In contrast, the reverse was true for PNES, where patients attributed the disorder to wholly or partially physical causes and neurologists only endorsed psychological causes (Whitehead et al., 2013). Illness perceptions, what people think of a condition, are important in the sense that they translate into clinically relevant behaviours (Hagger & Orbell, 2003). For example, a physician’s perception of a disorder can colour the way in which a patient perceives and thinks about their situation, even more so when the condition is associated with stigma (R. Thompson et al., 2009). Furthermore, Jackson and Kroenke (1999) state that the negative attitude

of a doctor toward a patient can be a predictor of poorer prognosis. Similarly, treatment outcomes are adversely influenced by differences in illness perceptions between patients and physicians, with a resultant increase in healthcare utilization (Heijmans, 1998; olde Hartman, Hassink-Franke, Lucassen, van Spaendonck, & van Weel, 2009).

To add to these difficulties, Piñeros, Rosselli, and Calderon (1998, p. 1427) lament the “ignorance and insensibility of Western-trained health professionals in dealing with other cultures.” In fact, Good, James, Good and Becker (2003) illustrate how student doctors are trained to treat the patient’s life narrative as irrelevant and are encouraged to reconstitute the patient’s social and cultural context and experience of illness into medically meaningful accounts. Fitzgerald (1992) argues that culture forms an integral part of every individual’s life, and encounters between physicians and patients can only be successful when cultural diversity is taken into account. Clinical interaction between a patient and an HCP includes at least three cultural systems: “(1) the personal or familial culture of the provider; (2) the personal or familial culture of the patient; and (3) the culture of the primary medical system” (Fitzgerald, 1992, p. 38). It is suggested that a fourth cultural influence, the traditional medical culture, should be taken into account when the patient or HCP comes from a non-Western background (Fitzgerald, 1992). However, the amount of shared knowledge in any given encounter may vary and lead to problems and misunderstandings when the patient and the HCP have little knowledge of the other cultures involved (Fitzgerald, 1992). For example, in a situation where the HCP hails from a biomedical background and the patient originates from a non-Western culture, the resultant multicultural interaction can be regarded as transactions between their individual explanatory models (EMs) (Fitzgerald, 1992). It is then not surprising that HCPs and patients frequently have different EMs about illness episodes (Bassett, 2011). Ultimately, the quality of the healthcare interaction depends on the degree to which these EMs are compatible (Bassett, 2011). According to Kleinman (1978, pp. 87–88), EMs are cultural, socio-political and historical products and contain explanations for illness episodes which include “etiology; onset of symptoms; pathophysiology; course of sickness (severity and type of sick role); and treatment.”

The role of culture, history and socio-political factors in EMs are illuminated by studies that focused on the knowledge, attitudes and perceptions towards epilepsy among HCPs in some African countries. In study conducted in Nigeria, 11.76 per cent of health service providers believed that epilepsy is transferable, while only 43.63 per cent believed that it is inheritable, 5.39 per cent believed that it is contagious and 8.08 per cent that it can be contracted through urine, while some doctors believed epilepsy to be caused by witchcraft and evil spirits (Ekeh, Akpan, & Ekrikpo, 2016). In the same study, only 84.8 per cent of HCPs believed that ES is treatable with 5.39 per cent believing that it is not and 2.45 per cent believing that it is not treatable in a hospital (Ekeh et al., 2016). Nineteen per cent of medical students in Uganda who

participated in a survey study indicated that ES can be contracted through bodily fluids and that ES can sometimes be caused by supernatural forces (Bigelow, Berrett, Kimuli, & Katabira, 2015). In a study performed among HCPs in Zambia, only 62.3 per cent of the 276 respondents' characterized epilepsy as a brain disorder, while more than half perceived it to be a mental illness and 89.8 per cent recognized that it required chronic medication (Chomba et al., 2007). It was interesting to note that in both the Nigerian and Zambian studies respondents expressed fear of PWE (Chomba et al., 2007; Ekeh et al., 2016).

So, whereas most HCPs are trained in biomedicine based on the dominant model of disease in Western culture, these views are not necessarily shared by the communities they serve or the practitioners themselves. These differences in illness perceptions between HCPs and patients often lead to misunderstandings and poorer outcomes (Stone et al., 2003). Consequently, HCPs' perceptions of the causes of seizures can influence outcomes. Communicating these perceptions to patients remains the first line of defence against disorders that can render patients helpless and frustrated with finding an explanation for their symptoms (Duncan, Graham, & Oto, 2014). It is therefore of the utmost importance that the relationship between physician and patient is such that the patient is prepared to engage in treatment. The manner in which a diagnosis is communicated to the patient has been identified as a crucial first step in initiating positive outcomes and better prognosis (Benbadis, 2005). In addition, an HCP who only focuses on the treatment of the patient's physical symptoms and who does not consider the patient's cultural beliefs and emotional disturbance, may create discontent and cause the patient to seek help from other service providers who are more willing to engage with the patient's emotional grievances (Helman, 1981). It is thus evident from the above discussion that whereas HCPs are trained to deal with the biological aspects of disease, difficulties arise when the focus moves to non-biological factors.

Towards this end, several studies explored the emotions and reactions of patients receiving a diagnosis of PNES. In the first survey, Carton, Thompson, and Duncan (2003) reported that 38 per cent of respondents who originally received an ES diagnosis that was later changed to a diagnosis of PNES, reacted with confusion, followed by 18 per cent with angry reactions and 21 per cent of patients indicating some relief and feeling free from the burden of ES. The next study was conducted with patients who had received the diagnosis of PNES in the preceding six months (Thompson et al., 2009). Themes identified in this study included being left in limbo land, doubts and uncertainties, feeling human again and various emotions that included relief, confusion, despair, feeling upset and unaffected anger (R. Thompson et al., 2009). The authors concluded that the overriding reaction among participants was that of helplessness, shame and anger with the need for support in the period between diagnosis and the onset of treatment (R. Thompson et al., 2009). A study done by Karterud et al. (2010) reported

very similar emotional reactions to the diagnosis of PNES. Reactions included relief, anger, shame and blame, and frustration with being taken seriously by the physician was identified as the most important factor. Finally, Fairclough, Fox, Mercer, Reuber, and Brown (2014) found in their study of PNES patients awaiting psychological treatment, that participants experienced a lack of support from health professionals and suffered from uncertainty about their condition. It is therefore evident that biomedicine faces several challenges when it comes to dealing with seizure disorders. The next section explores some of these issues.

Receiving a diagnosis of epilepsy can be a life-changing event and the impact may reverberate through various aspects of a person's life (Collard & Ellis-Hill, 2017; Hosseini, Sharif, Ahmadi, & Zare, 2013; Jacoby et al., 2008; Wo, Lim, Choo, & Tan, 2015). In a study conducted by Pembroke, Higgins, Pender, and Elliott (2017), patients described feelings of relief, anger, confusion, shame, stigma, fear and a desire to fit in as well as the realization that life adjustments are necessary. What was evident from this study was that the period to reach a definitive diagnosis of epilepsy was perceived as lengthy, sometimes taking months or even years (Pembroke et al., 2017). It is interesting that the same applies to PNES, where the average time to reach a diagnosis is reported as 7.2 years (Reuber et al., 2002). It is also reported that patients experience feelings of relief when they are finally able to put a name to their condition. However, this was followed by feeling upset, shocked, worried, angry and devastated (Pembroke et al., 2017). Many of these feelings are also experienced by PNES patients as described in the previous section. Feeling ashamed, overwhelmed, frustrated and self-conscious was also mentioned by participants in the ES part of the study and was linked to a lack of knowledge regarding epilepsy. This also brought on feelings of fear, confusion and reluctance to accept the diagnosis (Pembroke et al., 2017). Fear of stigma, discrimination and social rejection were prominent themes in a study conducted among ES patients in Iran (Hosseini et al., 2013). Other concerns included employment insecurity, educational setbacks and economic hardship with concomitant loss of self-esteem, prestige and the fear that one will become a burden to one's family and the community (Hosseini et al., 2013).

This section discussed how ES and PNES are traditionally perceived and treated by HCPs and patients and some of the misunderstandings and controversies regarding the disorders. The next section focuses on some of the challenges encountered in providing care to seizure patients.

## **2.16. Biomedical Healthcare Challenges**

Successfully diagnosing and classifying seizure disorders is one of biomedicine's biggest challenges. The misdiagnosis of ES is common, with false positives reported in up to 30 per cent of patients (Leach et al., 2005; Scheepers et al., 1998; D. Smith et al., 1999). The impact of misdiagnosis on the lives of patients is well documented and include the unwanted side-

effects of AEDs as well as the negative impact on psychosocial functioning (Baslet, Seshadri, Bermeo-Ovalle, Willment, & Myers, 2016; Guo et al., 2012; Xu et al., 2016). Misdiagnosis often results from a lack of knowledge about other conditions that look like ES, the over- and misinterpretation of EEG results, inefficient healthcare facilities, lack of training and experience among healthcare personnel, incomplete medical history taking and lack of funds for specialist care (Benbadis & Lin, 2008; Radhakrishnan, 2009; D. Smith et al., 1999; Xu et al., 2016).

Challenges continue with the treatment of ES, and notwithstanding the fact that the treatment for ES with AEDs seems fairly straightforward, it does present problems. The treatment gap with respect to access and provision of AEDs has been studied extensively (Guekht, Zharkinbekova, Shpak, & Hauser, 2017; Hunter et al., 2016; Meyer, Dua, Ma, Saxena, & Birbeck, 2010; Sebera et al., 2015; A. Singh & Trevick, 2016; Watila, Keezer, Angwafor, Winkler, & Sander, 2017). A systematic review of peer-reviewed literature published between 1978 and 2007 reported treatment gap estimates for active epilepsy in 54 populations from 28 countries and lifetime epilepsy in 18 populations from 28 countries (Meyer et al., 2010). The results from this study indicated global disparities in ES treatment, with an active epilepsy treatment gap of more than 75 per cent in low income countries, 50 per cent in lower middle- and upper middle income countries and less than 10 per cent in high income countries (Meyer et al., 2010). Wide treatment gaps were also identified between rural and urban populations, with a treatment gap of around 75 and 40 per cent respectively (Meyer et al., 2010). Although not statistically significant, treatment gaps decreased during the period studied, 1984–2004 (See Figure 2.4) (Meyer et al., 2010).

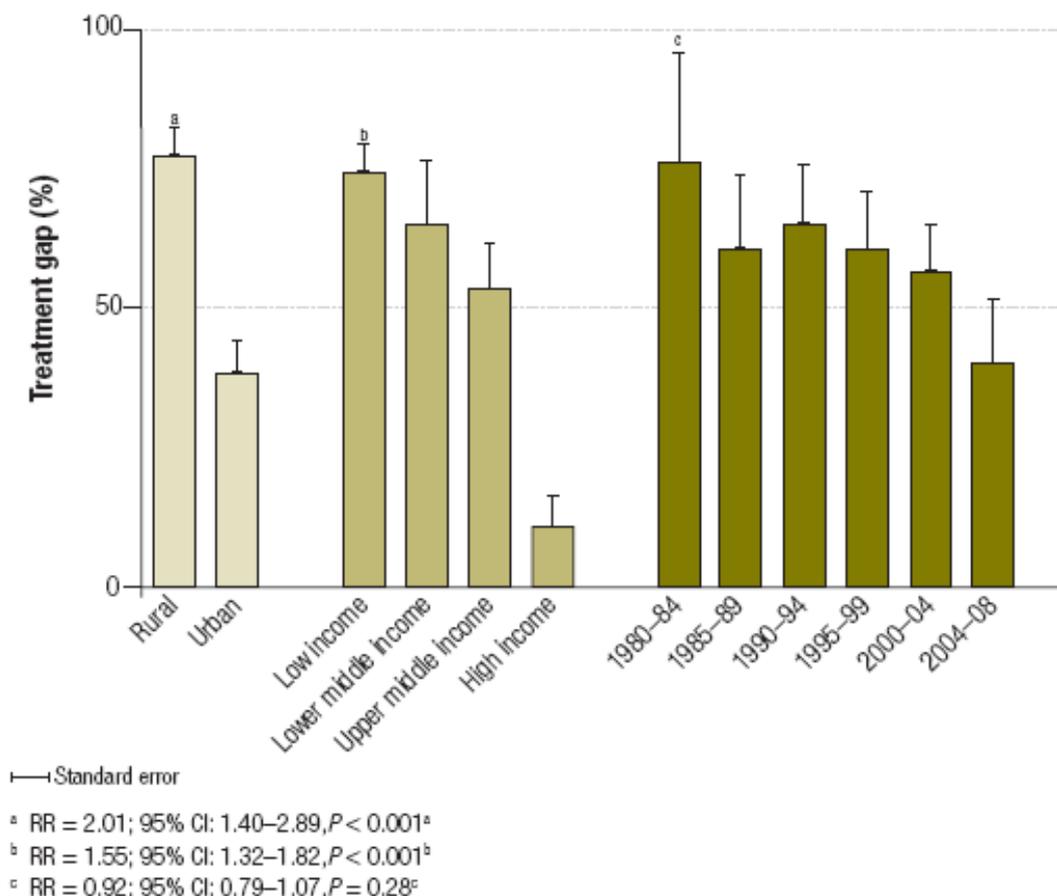


Figure 2.4. Mean epilepsy treatment gap (%) and standard errors by rural/urban status, World Bank income category and year that data were collected. Reprinted from Bulletin of the World Health Organization, Volume 88, Issue 4, Ana-Claire Meyer, Tarun Dua, Juliana Ma, Shekhar Saxena and Gretchen Birbeck, *Global disparities in the epilepsy treatment gap: a systematic review*, p. 263, 2010, with permission from the World Health Organization (see Appendix A4).

A follow-up study conducted by some of the same authors in 2012 reported a median treatment gap of 76 per cent for low, lower-middle and upper-middle income countries for the period 1982 to 2010 (Meyer et al., 2012). Factors that played a role in the treatment gap was reported as the country's economic gradient, healthcare availability, specialized neurological care and epilepsy-specific factors, as well as poverty measures, country debt and amount of aid received (Meyer et al., 2012). Other studies confirm that reasons for poor epilepsy care are complex and multifaceted, with a lack of expertise, availability of AEDs and monitoring equipment contributing to the treatment gap (A. Singh & Trevick, 2016; World Health Organization, 2005).

A far larger problem seems to be the discontinuation of AED treatment, which is seen as the secondary treatment gap (Das et al., 2007). Patient factors that play a role in the increased likelihood of non-adherence in Tanzania are reported as being male, believing in the supernatural

nature of ES, having seizure-related injuries and alcohol use (Hunter et al., 2016). Other contributing factors were cited as the affordability and accessibility of AEDs, the preference for traditional treatment and stigma (Hunter et al., 2016). Failure to seek medical treatment for ES in Kenya was attributed to traditional beliefs, negative attitudes towards biomedicine, travel distances to healthcare facilities and the cost of AED treatment (Mbuba et al., 2012). A study conducted in China ascribed the discontinuation of epilepsy treatment among patients to unemployment, income and cost of treatment disparity, socioeconomic and cultural reasons, lower education levels and non-availability of drugs (Das et al., 2007). A study from Kazakhstan reported an increased treatment gap in rural compared to urban populations and ascribed this to higher levels of ES stigma and the tendency to make use of traditional healers in these areas (Guekht et al., 2017). Sebera et al. (2015) found that only 16 per cent of the participants in a study conducted in Rwanda were on AED treatment and of these only 49 per cent managed to adhere to treatment on a regular basis. The authors reported reasons for non-adherence as a lack of funds, unavailability of AEDs and other personal reasons as stated by respondents (Sebera et al., 2015). Finally, a study that investigated the availability, price and affordability of five AEDs in 46 countries reported that the availability and affordability of AEDS in low and middle income countries are poor and may therefore contribute to the treatment gap (Cameron et al., 2012).

Surprisingly, none of the studies mentioned here make reference to the relationship between non-adherence and drug side effects and interactions as a reason for non-compliance. Some of these concerns have been raised by authors such as Kvalsund and Birbeck (2012) who investigated the interactions between AEDs and anti-retroviral medication. Therapeutic drug monitoring was also mentioned as a concern in low income regions where it was found to be as low as 45.1 per cent in Africa and 54.6 per cent in the western Pacific (Kvalsund & Birbeck, 2012). A possible explanation for the absence of the role of adverse effects as a reason for non-compliance to AED treatment might be patients' ignorance on the possible adverse effects and their willingness to accept it as part of life (Keikelame, Hills, Naidu, de Sá, & Zweigenthal, 2012). In addition, a lack of time, knowledge and the counselling skills necessary to inform patients about their illness and the effects of AEDs contribute to poor management and non-compliance (Krause, van Rooyen, van Vuuren, & Jenkins, 2007). As can be seen from the above discussion, challenges in the treatment of ES mostly relates to biomedical interventions in the form of medication, access to specialized services and economic factors. The picture for PNES looks very different and is discussed next.

The frustrations HCPs experience with the diagnosis and management of PNES can roughly be grouped into interactions with patients, difficulties experienced in diagnosing PNES, and a lack of collaboration between HCPs. A study that identified themes related to HCPs'

perceptions regarding treatment, diagnosis and attitudes about PNES was conducted by a group of researchers in the USA who formed part of the Veteran's Health Administration (McMillan et al., 2014). They suggest that treatment decisions and attitudes that influence provider behaviour may be shaped by several themes that reflect current problems in treatment and diagnosis (McMillan et al., 2014). The study centred on two domains, namely frustration and hope, where frustration manifested in themes and subthemes such as Disorder-related diagnosis (complexity and stigma); Provider attitudes (attitudes about challenging patients and primary/secondary gain); Treatment of PNES (uncertainty about treatment and patient in limbo); failure of cross-disciplinary collaboration; and referral issues. The results of this study, a first of its kind, represent "a starting point in identifying areas of common concern among clinicians caring for patients with PNES" (McMillan et al., 2014, p. 281).

In 2005, Benbadis lamented the lack of research aimed at PNES and concluded that psychogenic symptoms are somewhat taboo, generally 'avoided', seen as a source of frustration for physicians and that treatment is challenging. This viewpoint is reflected in two studies conducted by Monzoni, Duncan, Grünewald, and Reuber (2011a, 2011b) who used conversation analysis to study interactional patterns in an attempt to understand the challenges of clinical encounters between physicians and PNES patients. In this study, which focused on patients' interactional behaviour, resistance was found in all encounters. It was expressed overtly through rejections, disagreements and challenges, while silences, lack of engagement and minimal responses signified passive resistance (Monzoni et al., 2011a). The authors of the study concluded that physicians experience overt resistance as unpleasant and, therefore, try to refrain from provoking patients by being overly delicate and cautious in their approach (Monzoni et al., 2011a). This is confirmed by a subsequent study that explored doctors' interactional and linguistic resources when dealing with PNES patients. In this study, doctors engaged in consultations with a certain degree of defensiveness or prior concern that indicated interactional distress (Monzoni et al., 2011b). The above findings were also reflected in a study by Karterud et al. (2010) in which patients reacted negatively to a diagnosis of PNES. The diagnosis became a subject of defence instead of a collaborative effort to investigate the symptoms and to reach a shared understanding of the disorder.

The second area of frustration centres on difficulties experienced by HCPs in the diagnosis of PNES. Towards this end, Brown et al. (2011) recognize that HCPs, and specifically non-specialists, still find the differentiation of PNES from ES particularly challenging and conclude that this is a clear indication that more knowledge and skills are needed to distinguish PNES in clinical practice. The diagnosis of PNES is further complicated by the possibility that a patient could be faking and that detecting lies can be very difficult and possibly accusatory (Benbadis, 2005). While vEEG is considered the gold standard for the diagnosis of PNES,

disagreement as to its accuracy is reflected in a study conducted by Kanner (2003, p. 362), where 70 per cent of neurologists agreed that it is “an accurate diagnostic test” compared to only 18 per cent of psychiatrists. Kanner (2003) uses this as an example to illuminate the absence of “meaningful communication between the practitioners of these two specialities,” and ascribe poor outcome in PNES patients as being partly caused by this situation. What is more is that 35 per cent of HCPs also did not support the use of vEEG in the diagnosis of PNES in a study conducted by Sahaya et al. (2012).

Possibly the biggest frustration and source of concern is the absence of collaboration and agreement amongst HCPs regarding treatment and patient communication. For example, Bora et al. (2011) argue that there is a lack of cooperation at many epilepsy centres. This was illustrated by the fact that 91 per cent of PNES patients in their study were prescribed unnecessary AEDs as a result of neurologist intervention without the assistance of a psychiatrist. Kanner (2003) calls the lack of cooperation between neurologists and psychiatrists a *bizarre phenomenon* and professes that the future of PNES patients looks bleak as long as psychiatrists and neurologists function in isolation.

The management of PNES requires a team effort that starts with reaching a correct diagnosis, and after that “the initial phase of treatment is engagement” (Baslet et al., 2015, p. 56). To reiterate the importance of the successful delivery of the diagnosis, Baslet et al. (2015) state that this should occur in a multidisciplinary setting with an objective discussion of the findings and a clear indication that the HCP believes the symptoms to be real, followed by an explanation of the nature of the disorder and motivations for mental health treatment. Ideally, this phase should be conducted by a neurologist or general practitioner, with a psychiatrist or psychologist in attendance to avoid possible contradictory and harmful information from reaching the patient and family (Baslet et al., 2015; Kanner, 2010). The importance of coordination and efficient communication between neurologists, psychiatrists, psychologists, GPs and patient, family and care providers play a crucial role in treatment success (LaFrance Jr. & Devinsky, 2004). Unfortunately, psychiatrists often refuse to accept the diagnosis of PNES, even in cases where it was established by vEEG, and this creates an obstacle to successful treatment (Kanner, 2010). This opinion of psychiatrists is based on responses collected in a survey that was conducted with neurologists and psychiatrists while attending a symposium about PNES. Seventy-five per cent of psychiatrists indicated “that they ‘do not trust’ the data derived from vEEG sufficiently to reach a diagnosis of PNES” (Kanner as cited in Kanner, 2010). This is further complicated by the sometimes limited access to psychiatrists and insufficient communication and conflicting opinions between neurologists and psychiatrists (Kanner, 2003, 2010). However, the role of the psychiatrist is vital in rendering psychotherapy and pharmacotherapy during treatment, as 50 per cent of patients with PNES also suffer from

severe psychiatric disorders (Kanner, 2010). The next phase involves the services of neuropsychologists and clinical psychologists to establish acute interventions with the primary goal of seizure reduction and improvements in quality of life, psychiatric comorbidities, medical resource utilization and functional recovery (Baslet et al., 2015). This is followed by the final phase of treatment, which comprises long-term interventions that may include social workers or psychiatric nurses and other healthcare providers who may be more cost-effective and can address the patient's social needs and concerns (N. C. Thompson & Gibson, 2010).

In an interesting study conducted by Baslet and Prenskey (2013, p. 63), patient adherence to treatment was investigated by using *integrated intervention*, "treatment conducted in the same institution" and *divided intervention*, "psychiatric management offered in different settings." It was found that 50 per cent of patients using *integrated intervention* remained engaged after five sessions, whereas 31 per cent complied in the *divided intervention* group (Baslet & Prenskey, 2013). The authors concluded that marital status was the only predictor for engagement and illustrated that PNES patients struggle to remain compliant to mental health services (Baslet et al., 2015). Although it is not explicitly stated in this study, one cannot help to surmise whether the benefits of the integrated intervention might also be as a result of improved collaboration between the various HCPs in the same institution. At the same time, there is a limited understanding and no standardized method for the most efficient way to provide a transition of care between disciplines, and this may partly explain the low rates of treatment compliance observed in PNES patients (Baslet et al., 2015). Interdisciplinary collaborative efforts may therefore prevent the loss of patients who "fall through the cracks between disciplines," and HCPs should embrace their role in the management of this disorder (Baslet et al., 2015; LaFrance Jr. & Barry, 2005, p. 372).

### **2.17. Traditional Medicine**

The second healthcare system available to the Namibian population is traditional medicine. The WHO defines TM as the "sum total of the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health, as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness" (World Health Organization, 2013, p. 15). The definition published by WHO in 2005 seems more clear and sees TM as "including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal, and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness" (World Health Organization, 2002). For the purposes of this discussion it is important to outline the goals, objectives and challenges encountered by the WHO in setting the Traditional Medicine Strategy. The goals of the strategy include (World Health Organization, 2013, p. 11):

- harnessing the potential contribution of TM to health, wellness and people-centred health care;
- promoting the safe and effective use of TM by regulating, researching and integrating TM products, practitioners and practice into health systems, where appropriate.

“The strategy aims to support Member States in developing proactive policies and implementing action plans that will strengthen the role TM plays in keeping populations healthy. It seeks to build upon the WHO Traditional Medicine Strategy 2002–2005, which reviewed the status of TM globally and in Member States, and set out four key objectives” (World Health Organization, 2013, p. 11):

- policy — integrate TM within national health care systems, where feasible, by developing and implementing national TM policies and programmes.
- safety, efficacy and quality — promote the safety, efficacy and quality of TM by expanding the knowledge base and providing guidance on regulatory and quality assurance standards.
- access — increase the availability and affordability of TM, with an emphasis on access for poor populations.
- rational use — promote therapeutically sound use of appropriate TM by practitioners and consumers.

Challenges related to these goals and objectives include (World Health Organization, 2013, p. 12):

- development and enforcement of policy and regulations;
- integration, in particular identifying and evaluating strategies and criteria for integrating TM into national and primary health-care (PHC);
- safety and quality, notably assessment of products and services, qualification of practitioners, methodology and criteria for evaluating efficacy;
- ability to control and regulate TM and Complementary Medicine (T&CM) advertising and claims;
- research and development;
- education and training of T&CM practitioners;
- information and communication, such as sharing information about policies, regulations, service profiles and research data, or obtaining reliable objective information resources for consumers.

Based on the above goals and objectives, an overview of the TM situation in the African region (Kasilo, Trapsida, Mwikisa, & Lusamba-Dikassa, 2010) report that 39 out of 46 countries in Africa have National TM offices and 24 have TM programmes in their Ministries of Health.

Namibia, Botswana and Algeria are the only countries in this region for which no information is available (Kasilo et al., 2010). At the moment, THPs in Namibia, many of whom hail from other African countries, have no legally defined status. Despite the lack of specific data on THPs in Namibia, the last known estimates indicate that there are approximately 2 400 THPs actively operating in the country (Marshall, 1998).

Prior to Namibia's independence, TM was outlawed in the country (World Health Organization, 2001). Since its legalization in 1990, several attempts have been made to regulate and formalize the practice of TM. One such an attempt was the establishment of the Namibia Eagle Traditional Healers Association (NETHA) in 1990 with the aim to professionalize and organize THPs (Lebeau, 1999; Waters Lumpkin, 1993; World Health Organization, 2001). However, this organization and others of its kind seem to have gone to ground and no recent information on its activities is available. The National Policy on Community-based Health Care, issued in 2008, made the following statements regarding THPs in Namibia (Ministry of Health and Social Services, 2008):

“Community based traditional health practitioners actively complement the work of the government in an effort to provide much needed support to community members especially in the area of health and social services (p. 6);

Traditional healers are highly respected in communities and community members have confidence in their information. Traditional healers have immense influence in their communities and can present a positive or a negative force towards the promotion of health and development, depending on their conviction and involvement (p. 12); and Monitoring and coordination between the community, the health facility and traditional healers will be strengthened. The specific roles and responsibilities outlined in the Traditional Health Practitioners legislation (to be promulgated) will be adhered to” (p. 14).

However, the Traditional Health Practitioners Bill, which was tabled in the National Assembly in 2014, is yet to be promulgated and the status of THPs in the country remains unclear and unregulated.

Notwithstanding these challenges, the practice of TM seems widespread throughout the country, although it seems to be more dominant in the northern regions of the country (Lebeau, 1999; Waters Lumpkin, 1993) (see Figure 2.5).



generation to generation through oral tradition and some form of apprenticeship (Thornton, 2009). As a result, these practices can be inconsistent, non-standardized and undocumented (Meincke, 2012). African healing practices are also not universal, but rather personal and particular to an individual patient with treatment that focuses on the specific circumstances of the patient and the healer (Meincke, 2012). This is in stark contrast to the biomedical framework, which is based on scientific enquiry and where disease is seen as universal, treatment as similar across all modalities and where there is little room for the social, psychological and behavioural dimensions of disease (Engel, 2012). These differences between the biomedical and traditional healthcare systems and the perception that biomedicine dominates in the field of healthcare often lead to distrust between HCPs and THPs (Cooper, 2016; Morris, 2000).

Notwithstanding the animosity between biomedicine and TM, a growing demand for TM is reported across the world (Abdullahi, 2011). A number of factors are responsible for the increased interest and widespread use of TM. For instance, in Africa TM is used to meet the healthcare needs of approximately 80 per cent of the population and in China, 40 per cent of all healthcare is based on TM (World Health Organization, 2002). Accessibility plays a major role in the widespread use of THPs in Africa where there is a lack of skilled medical doctors in general and where healthcare services are often located in urban areas (Abdullahi, 2011; Radhakrishnan, 2009). Cultural beliefs and heritage also play a role in people's motivation to seek healthcare from THPs, as is the case in many African countries as well as in Asia and Latin America (Abdullahi, 2011; World Health Organization, 2002). Another reason for the increased utilization of TM is the use of medicines in the form of plant, animal and mineral materials to treat a wide spectrum of diseases (Abdullahi, 2011; Okigbo & Mmeka, 2006). According to Okigbo and Mmeka (2006, p. 83), "These medicinal plants have more beneficial effect than their synthetic counterparts through being safer, acceptable, affordable, culturally compatible and suitable for chronic treatments." It is then not surprising that in developed countries where affordability, accessibility and cultural compatibility plays a lesser role, these medicines are preferred due to the increased awareness and concerns about the adverse effects of chemical compounds (World Health Organization, 2002).

Health-seeking behaviour is a multifaceted process based on a combination of political, structural and social factors (Cooper, 2016). Furthermore, health-seeking behaviour in Africa is a multi-layered process grounded in a kaleidoscopic range of healing styles and therapeutic preferences (Read, 2012; Read et al., 2009). For example, "clients choose health care treatment modalities according to their own worldviews (or reality-constructs), which may differ significantly from the biomedical model. Clients often use a variety of health care modalities, choosing different treatments for different problems, or clients may use whatever health care treatment is available, particularly if choice is limited" (Waters Lumpkin, 1993, p. 5). A pilot

study conducted in Windhoek and Katutura, an African township neighbouring on Windhoek, found that THPs play a major role in primary healthcare and social welfare among the disadvantaged population in Namibia (Waters Lumpkin, 1993). In Namibia, many patients with seizures may first seek treatment from a biomedical HCP, although a diagnosis of an incurable, but controllable disease is often deemed unacceptable and in some cases prompt patients to seek treatment from a THP (Lebeau, 1999). Waters Lumpkin (1993) state that HCPs are often perceived as poor communicators and that people find THPs more empathetic and easier to approach. The majority of people in Namibia reside in rural parts of the country, with limited access to specialized services and equipment. It is therefore not surprising that people with seizures may seek care from THPs who are physically more accessible, who provide greater cultural and conceptual understanding and whose EM for seizures is possibly closer to those of the people they serve.

Cultural and societal concepts traditionally associate the manifestation of seizures with divine or demonic possession, witchcraft and supernatural forces (Chaudhary et al., 2011; de Boer, 2010; Institute of Medicine, 2012). For example, in many African countries it is traditionally believed that seizures manifest as a result of a spiritual disease that is caused by witchcraft, curses, spirits or demonic possession arising outside of the affected person (Baskind & Birbeck, 2005a; Ekeh & Ekrikpo, 2015; Kendall-Taylor, Kathomi, Rimba, & Newton, 2008; Lebeau, 1999). In Namibia, THPs accept that natural causes can contribute to the manifestation of seizures although spiritual causes are also recognized (Lebeau, 1999). In a study on health-seeking behaviour in Katutura, adjacent to Windhoek, it was found that all THPs treat seizures (Lebeau, 1999). Causes for seizures are ascribed to witchcraft, evil spirits (a social or spiritual cause) or considered to be due to genetic or natural causes (Lebeau, 1999). It is also believed that once the correct medicine is found, any illness, including seizures, can be cured (Lebeau, 1999; Waters Lumpkin, 1993). As can be seen from the above beliefs regarding the causes of epilepsy in TM, a distinction is made between the physical (genetic or natural) and psychological (spiritual or social) origin of the seizures. This understanding corresponds with the biomedical view of seizures as a result of MES and MUS.

In Namibia, very little is known about THPs' knowledge regarding the management of seizures save for the two studies performed by anthropologists approximately two decades ago. There are no published studies on collaboration or even mutual points of interest between HCPs and THPs in Namibia. This study will be a first for Namibia and will provide some information about practitioners' perceptions of each other and the ways in which they deal with seizures. This study may also contribute to some of the WHO's objectives by providing insight into the current state of TM in Namibia.

## 2.18. Theoretical Framework

The role of theory in a research project can be described as a “lens” through which phenomena are studied. It enables the researcher to illuminate specific aspects of the phenomena while masking others (Anfara Jr. & Mertz, 2006, p. 15). The theory, therefore, plays a critical role in framing and conducting every phase of a research study (Anfara Jr. & Mertz, 2006). As such, a theoretical framework is used to guide an investigation by connecting assumptions, fundamental beliefs and purposes for conducting the specific study (Anfara Jr. & Mertz, 2006).

The “lens” I wanted to use while looking at the perceptions and frustrations experienced by HCPs and THPs had to be narrow enough to focus on the HCP and THP individually, but also broad enough to embrace the landscape surrounding them. To include the surrounding environment, I looked at ecological models that include a focus on the individual. For purposes of this study, ecology can be defined as “the interrelations between human beings and their environments” (L. W. Green, Richard, & Potvin, 1996, p. 270). Two models that focus on the interrelationships between individual behaviour and its environmental determinants are the social ecological model (McLeroy, Bibeau, Steckler, & Glanz, 1988), which explains human behaviour at the hand of five levels of analysis (intrapersonal factors, interpersonal processes, institutional factors, community factors and public policy) and Bronfenbrenner’s earlier ecological systems theory (EST) (1977, 1979), which states that forces surrounding the individual comprise of interdependent systems that constitute the ecological environment.

The difference between the two theories mentioned above is the direction from which it approaches the research problem. The social ecological model focuses its attention on environmental interventions that change individual behaviour, whereas EST allows for attention to “both behaviour and its individual and environmental determinants” (McLeroy et al., 1988, p. 354). It was for this reason that I chose EST. It places emphasis on the processes in and between interrelated social systems and the individual, which enables one to investigate the perceptions and frustrations of HCPs and THPs and how these impact on patients, other healthcare professionals and the broader social context but also how these impact on the HCP and the THP (Bronfenbrenner, 1977). Bronfenbrenner seemed to be his own fiercest critic and continually revised, altered and extended his theory. This ultimately led to the development of the bioecological theory of human development, which was published in 2005, also the year of his death (Tudge, Mokrova, Hatfield, & Karnik, 2009). However, EST is not without its critics, as Watling Neal and Neal (2013, p. 723) reveal in an article that argues that “the precise relationship of subsystems to one another remain elusive.” In their article, they point out that the various relationships between the systems are obscured when seen as ‘nested’ within one another. These relationships should rather be conceptualized as ‘networked’, in other words, overlapping but non-nested. They also offer alternative descriptions for the micro-, meso-, exo-

and macro-systems that align with the networked view. They conclude that this view provides EST with greater flexibility and a better understanding of the relationships between the different systems (Watling Neal & Neal, 2013). Notwithstanding this criticism, EST provides me with the most suitable framework with which to view the perceptions and frustrations of HCPs and THPs.

According to Bronfenbrenner's EST (1979), human behaviour can be considered in terms of a hierarchy of related systems with interactional patterns between and within the systems (Moore, 2003). Bronfenbrenner describes it as "a nested arrangement of structures, each contained within the next" (Bronfenbrenner, 1977, p. 514). The EST is used in the present study as it enables one to describe how the perceptions of HCPs and THPs could influence the various interrelated systems that form part of the diagnosis and treatment of seizures.

Four levels of interaction are outlined in the EST (Bronfenbrenner, 1977) namely the micro-, meso-, exo- and macro-systems. Bronfenbrenner (2005) added another dimension to later work, namely the chronosystem. The different levels describe individuals as part of subsystems, which in turn form part of a larger supra-system. The person as an individual is seen as the centre of the entire system, with the various systems forming permeable and bidirectional layers around the person. The key to this theory lies in the "interaction within the layers of the structures and the interaction of the structures between the layers" (Härkönen, 2007, p. 7). The person is made up of various levels of knowledge, skills, self-confidence, perceptions, frustrations and motivations and has different roles, that influence the patterns of interaction with and within the different systems (Gregson et al., 2001; McLeroy et al., 1988). The person in the present study is the HCP or THP in the role of service provider, rendering a service as a private practitioner. The HCP or THP have varying levels of training and expertise and have certain attitudes and beliefs. The first layer surrounding the person is called the microsystem.

The microsystem can be described as the pattern of the activities and the interpersonal relationships of a person who assumes a specific role in a particular place, with another person in a face-to-face setting (Bronfenbrenner, 1977; Härkönen, 2007; Visser, 2012). Bidirectional interactions are strongest in the microsystem and behaviours can be influenced by the attitudes and actions of others (Gregson et al., 2001; Härkönen, 2007). In this study, the pattern of interaction between the HCP or THP, the patient, the family of the patient and other HCPs and THPs can be described as forming the microsystem of the HCP and the THP.

The mesosystem refers to the linkages between the various microsystems in which the HCP or THP participates and can be described as a system of microsystems (Bronfenbrenner, 1979). The inter-relationships between the different microsystems can play a major role in how the person experiences the mesosystem (Härkönen, 2007). Conflict or disagreements may arise in the mesosystem if the structures in the microsystems oppose each other or cultivate different beliefs and expectations (Härkönen, 2007). An example of this level of influence would be the

positive or negative interactions that take place between the patient, family members of the patient and other HCPs and THPs without the direct involvement of the HCP or THP who forms the centre of the system.

The exosystem can be seen as an extension of the mesosystem and includes both formal and informal social structures that influence and delimit the person, even though these structures do not directly contain the person (Bronfenbrenner, 1977; Visser, 2012). Therefore, the person may be seen as a participant in these structures, but not necessarily a member (Härkönen, 2007). Structures in the exosystem may include institutions or organizations responsible for regulating or providing services to the healthcare industry. This may include medical aid funds, professional organizations, and healthcare infrastructure such as hospitals, clinics, providers of equipment and medication and referral practices. Once again, the relationships between the various structures in the exosystem are rated as positive or negative, and this will ultimately affect the HCP or THP's perception of the exosystem.

The macrosystem refers to the wider societal and cultural norms, such as policies regarding health and economic standards, legal and political systems, attitudes and belief systems, as well as cultural values (Bronfenbrenner, 1977; Visser, 2012). Bronfenbrenner explains that "Macrosystems are conceived and examined not only in structural terms but as carriers of information and ideology that, both explicitly and implicitly, endow meaning and motivation to particular agencies, social networks, roles, activities, and their interrelations" (1977, p. 515). The macrosystem encompasses all the other layers and as such penetrates and influences every structure in the micro-, meso-, and exosystems. An example could include the government's decision to move the responsibility of providing healthcare services to individual communities without offering adequate infrastructure to support this decision or formally recognizing the role of THPs in these communities.

The EST was used to interpret and describe the perceptions and frustrations experienced by HCPs and THPs holistically by interpreting the ideas and understandings they have of seizures, themselves and their environments.

## **2.19. Summary**

This chapter provided an overview of the literature on seizures with a specific focus on the role of the biomedical and traditional medical frameworks in the management of these disorders. First, an outline of the classification and epidemiology of seizures was discussed followed by the historical background of the evolvement of information on seizures. Next, a comprehensive account of the clinical picture, the aetiology of ES and PNES and the mechanisms underlying PNES was provided, as well as the diagnostic techniques and treatment options for ES and PNES. After that, the available literature on the prognostic factors and the

social and socioeconomic burden of seizure disorders were discussed. Biomedical healthcare services were described, together with the challenges experienced by biomedicine. The chapter concluded with a description of traditional medicine, followed by an outline of the theoretical framework that was used to interpret the findings of this study. The next chapter focuses on the research methodology that was utilized in the present study.

### Chapter 3: Method

This chapter discusses the research methodology employed in this study. First, the chapter outlines the research rationale and motivation for the study. After that, the research question and aims and objectives of the study are presented. The discussion then turns to the research design, description and selection of participants and the data collection procedures. This is followed by a discussion of the data analysis procedures and the processes used to ensure trustworthiness. Finally, the ethical considerations applied to the study are described.

#### 3.1. Introduction

The aim of this study is to investigate the diagnostic and treatment services offered by biomedicine and traditional medicine (TM) in order to provide an inclusive view of the known healthcare options available to patients with seizures in Namibia. Simultaneously, the study aims to identify the perceptions and experiences of the people who render these services to lay the foundation for future studies on how to improve the quality of care for seizure patients in Namibia. Towards this end, the study uses Bronfenbrenner's ecological systems theory (1977, 1979) to conceptualize the discussion of the perceptions and experiences of healthcare providers (HCPs) and traditional health practitioners (THPs) regarding the management of seizures..

#### 3.2. Research Design

In an effort to investigate the perceptions and experiences of HCPs and THPs regarding the diagnosis and treatment of seizures, I utilized a basic concurrent, cross-sectional, mixed method research design. Johnson and Onwuegbuzie (2004, p. 17) define mixed methods research as "the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study."

A plethora of studies have been performed that describe, analyse, define and criticize mixed method research (Barnes, 2012; Bazeley, 2008; Creswell, Klassen, Plano Clark, & Clegg Smith, 2011; Hesse-Biber, 2015; Ivankova, 2014; Johnson & Onwuegbuzie, 2004; Kelle, 2005; Leech & Onwuegbuzie, 2009; Östlund, Kidd, Wengström, & Rowa-Dewar, 2011; Tashakkori & Teddlie, 2009). What is evident from the literature is that a novice researcher could become overwhelmed by the intricacies of mixed method research and for this reason I attempted to derive as much benefit from a mixed design without overly complicating the research methodology.

The motivation for using a mixed research design stemmed from the potential benefits of such a study compared to a monomethod study. Literature furthermore suggests that policy makers draw on both quantitative and qualitative evidence in an attempt to comprehend the barriers to access to healthcare (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005).

Johnson and Onwuegbuzie (2004, p. 18) argue that with the use of multiple data collection strategies and the combination of these, the resultant mixture “is likely to result in complementary strengths and nonoverlapping weaknesses” and claims that the outcome will “be superior to monomethod studies.” Using the qualitative and quantitative approaches in a complementary manner provides the researcher with the opportunity to examine different perspectives on the research problem in an attempt to develop a fuller picture of the problem at hand (Woolley, 2009).

Another reason for using a mixed method design was the lack of available statistics on PNES and ES in Namibia. In exploring the perceptions and experiences of HCPs and THPs about seizures, the different data sets provided a more comprehensive picture of the context in which HCPs and THPs function. The aim was, therefore, to use survey data to detect practices underlying HCPs and THPs perceptions and experiences regarding seizures (Woolley, 2009). An overview of the research design and the content of the ‘Manuscript Chapters’ 4, 5, 6 and 7 are summarized in graphic and table form below (see Figure 3.1 and Table 3.1).

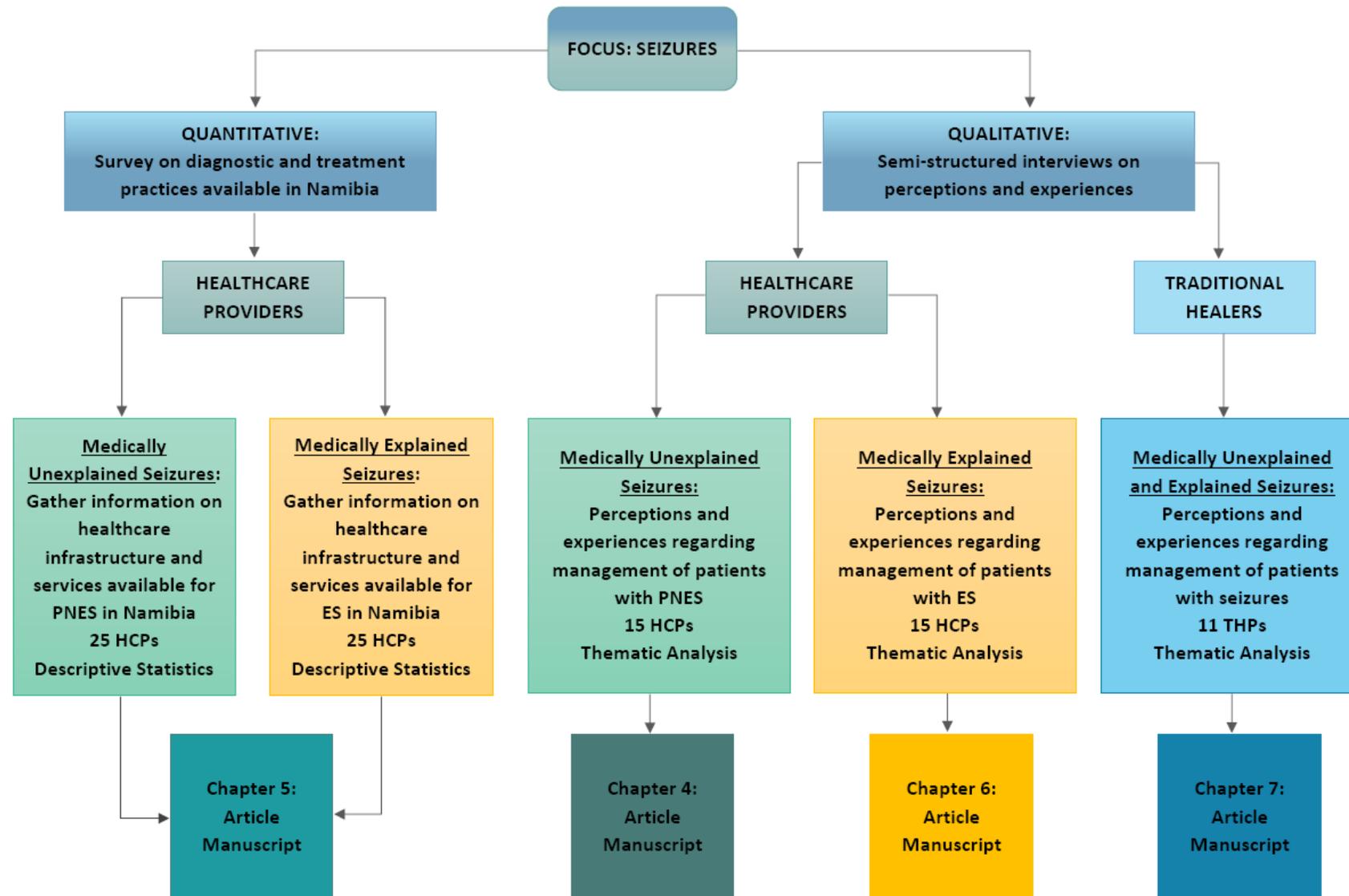


Figure 3.1. A graphic illustration of the research design of the study.

Table 3.1. *Overview of the research design of the study.*

<i>Chapter</i>	<i>Operationalization</i>	<i>Method of data collection</i>	<i>Method of data analysis</i>
4	Eliciting HCP perceptions and experiences regarding management of PNES	<ul style="list-style-type: none"> <li>• Qualitative</li> <li>• Purposeful sampling</li> <li>• Semi-structured interviews</li> <li>• 15 HCPs</li> </ul>	<ul style="list-style-type: none"> <li>• Thematic analysis</li> </ul>
5	Investigating current diagnostic and treatment practices for PNES in Namibia	<ul style="list-style-type: none"> <li>• Quantitative</li> <li>• Purposeful sampling</li> <li>• ILAE PNES TF Survey for HCPs</li> <li>• 25 HCPs</li> </ul>	<ul style="list-style-type: none"> <li>• Descriptive statistics</li> <li>• Frequency distributions</li> <li>• Percentages</li> <li>• Means and ranges</li> </ul>
	Investigating current diagnostic and treatment practices for ES in Namibia	<ul style="list-style-type: none"> <li>• Quantitative</li> <li>• Purposeful sampling</li> <li>• ILAE ES Survey for HCPs</li> <li>• 25 HCPs</li> </ul>	<ul style="list-style-type: none"> <li>• Descriptive statistics</li> <li>• Frequency distributions</li> <li>• Percentages</li> <li>• Means and ranges</li> </ul>
6	Eliciting HCPs' perceptions and experiences regarding the management of ES	<ul style="list-style-type: none"> <li>• Qualitative</li> <li>• Purposeful sampling</li> <li>• Semi-structured interviews</li> <li>• 15 HCPs</li> </ul>	<ul style="list-style-type: none"> <li>• Thematic analysis</li> </ul>
7	Eliciting THPs' perceptions and experiences regarding the management of seizures	<ul style="list-style-type: none"> <li>• Qualitative</li> <li>• Snowball sampling</li> <li>• Semi-structured interviews</li> <li>• 11 THPs</li> </ul>	<ul style="list-style-type: none"> <li>• Thematic analysis</li> </ul>

### 3.3. Description of Participants

Similar studies in the UK, Ireland, Chile and the USA have focused on the inclusion of neurologists, psychiatrist, epileptologists, neurosurgeons and neuroscientists (LaFrance Jr. et al., 2012; Mayor, Smith, & Reuber, 2011). Due to a scarcity of specialists, studies that focus on the knowledge and attitudes towards ES in Africa frequently include non-specialist physicians as is

the case in this study (Chomba et al., 2007; Ekeh et al., 2016; Ekeh & Ekrikpo, 2015). According to the Ministry of Health and Social Services Essential Indicators Database 2006–07 as reported in the WHO Regional Office for Africa Country Cooperation Strategy (WHO Regional Office for Africa, 2010), Namibia has 557 medical practitioners, which include dentists, psychologists and pharmacists. Namibia currently has two psychiatric wards, one in Windhoek and another in Oshakati with facilities that cater for approximately 200 patients in total. The unit in Oshakati has access to one psychiatrist and one neurologist who is in private practice. There used to be seven psychiatrists in Namibia in total, of which four were in private practice in Windhoek, two in state employ and one in private practice in Swakopmund. One psychiatrist in Windhoek recently left the country (2017). Namibia is served by three neurologists, two of whom are situated in Windhoek and the other in Oshakati in the far north of the country. Two neurosurgeons are in private practice in Windhoek and none in the rest of the country.

According to the WHO, Namibia has 0.374 physicians per 1 000 people, 12 psychiatric beds per 100 000 people, 4.78 CT units, 0.87 MRI units and 0.77 EEG monitors per million people (World Health Organization, 2016). No video-EEG monitors, which are known as the gold standard for diagnosing PNES, are available in the country and nor are there any epilepsy monitoring units. Approximately 20 clinical psychologists practice privately in Windhoek and roughly the same number in the rest of the country, mainly situated in the coastal region. Mental healthcare services are predominantly provided in and around Windhoek for patients with access to medical aid funds (WHO Regional Office for Africa, 2010).

Governing bodies for healthcare providers are limited to the Ministry of Health and Social Services (MoHSS), the Health Providers Council of Namibia (HPCNA), Namibia Medical Aid Fund Administrators (NAMAF) and other private bodies. No organizations or societies exist for neurologists or psychiatrists specifically.

There is currently no official regulating body for traditional healers in Namibia, and although the Traditional Health Practitioners Bill has been in the pipeline for the past five years, it is yet to be ratified. It does seem, however, that two informal organizations in Namibia, namely the Namibian Traditional and Spiritual Healers Association (NTSHA) and Namibia Eagle Traditional Healers Association (NETHA) have attempted to play some regulatory role among THPs, although the researcher could not succeed in contacting them for participation in this study (Insight Namibia, 2006; Waters Lumpkin, 1993).

Purposeful sampling was used to identify potential participants from the available HCP pool in Namibia. The eligibility for participation in the study was based on the speciality of the HCP and excluded participants under the age of 21. HCPs were sourced from the private healthcare sector, taking into consideration that the public sector employs few specialists. Involving psychiatrists and neurologists in the study was vital considering the limited availability

of specialists. General practitioners (GPs) were identified based on experience in managing epilepsy and PNES patients, years in practice and special interest in neurology and psychology. In the PNES part of the study, participants were also recruited from the mental healthcare sector. The reason for including psychologists was the fact that PNES is largely treated by mental health professionals, as is evident from the literature review. It was therefore deemed necessary to include these HCPs in the PNES sample. With respect to the ES part of the study, mental health professionals were not included. Again, the reason for this decision was based on the fact that ES is largely seen as MES and according to the literature, the management of PWE is largely taken care of by GPs, neurologists and in some cases psychiatrists. It was as a result of these decisions that the samples for the ES and PNES parts of the study differed in its composition. It also necessitated the recruitment of additional GPs to partake in the ES part of the study to reach the required sample size. Whereas both the neurologists partook in both the ES and the PNES parts of the study, the same is not true for the GPs. Some GPs indicated their willingness to participate in both studies, but some elected to participate in either the ES or the PNES part. The reason for this decision may relate to their confidence, or lack of confidence, in diagnosing and treating PNES.

The two informal bodies for THPs, NTSHA and NETHA, do not seem to be in existence anymore. I was unable to make contact with representatives of these organizations, and their contact information delivered no response. Snowball sampling was therefore used to identify possible THPs who would be prepared to participate in the study.

### **3.3.1 HCPs' perceptions of and experiences with the management of PNES.**

A total of 15 participants were recruited to participate in this qualitative phase of the study. The participants consisted of three psychiatrists, two neurologists, six GPs, two clinical psychologists, one educational psychologist and one psychological counsellor. Years in practice ranged from five to 34 years (median = 24) and average age from 28 to 60 years (mean = 47). Nine of the participants were male, while the remaining six were female. The participants consisted of four Black, two Mixed and nine White individuals (see Table 3.2).

Two of the GPs indicated a special interest in psychiatry and psychology, while other GPs indicated specialization in allergies, occupational health and family medicine. The two clinical psychologists both specialize in forensic psychology and neuropsychology. One of the psychiatrists specializes in child and adolescent psychiatry. Except for one participant who lives in Swakopmund, all reside in Windhoek.

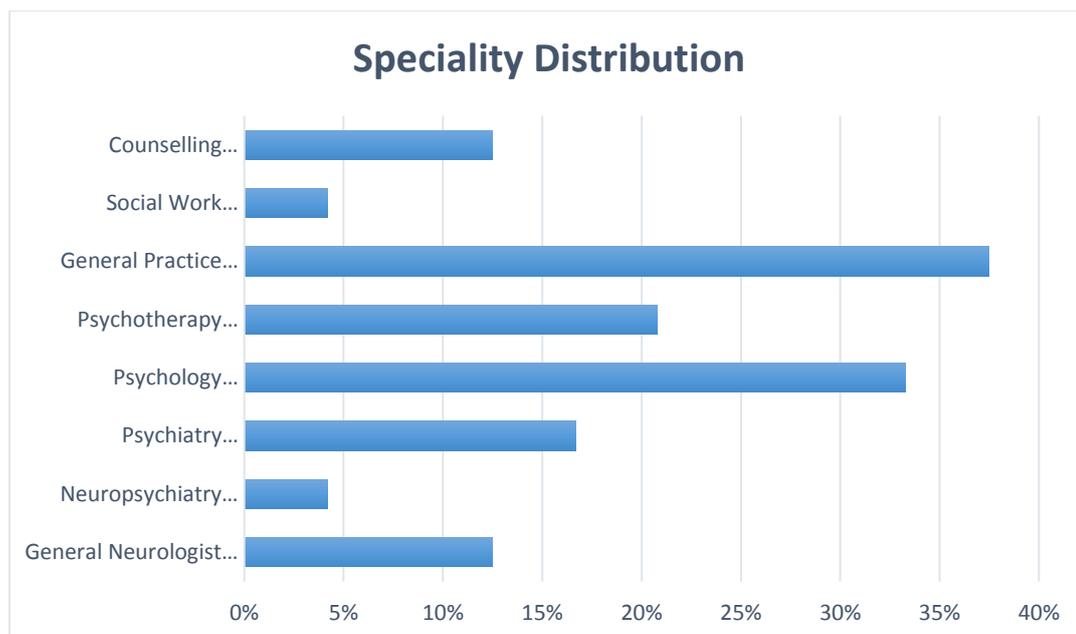
Table 3.2. *Demographic description of the HCPs who participated in interviews on their perceptions and experiences regarding the management of PNES.*

<i>Participant Code</i>	<i>Age</i>	<i>Gender</i>	<i>Race</i>	<i>Qualification</i>	<i>Years in practice</i>
A1	39	Male	Black	Neurologist	14
A2	38	Male	Black	Clinical Psychologist (PhD)	17
A3	47	Female	White	General Practitioner	21
A4	57	Male	White	General Practitioner	30
A5	37	Female	Mixed	Clinical Psychologist	10
A6	47	Female	White	Psychiatrist	24
A7	37	Female	White	Psychiatrist	13
A8	57	Male	White	General Practitioner	30
A9	60	Female	Black	General Practitioner	30
A10	52	Male	White	General Practitioner	25
A11	28	Female	Mixed	Psych Counsellor	5
A12	58	Male	White	Psychiatrist	32
A13	35	Male	Black	Neurologist	10
A14	53	Male	White	General Practitioner	25
A15	60	Male	White	Educational Psychologist	34
	<b>Mean 47</b>	<b>M: 60%</b>	<b>4B;2M;9W</b>		<b>Median 24</b>

Participant code: A = First set of interviews; 1 = Number of interview

### 3.3.2 Current diagnostic and treatment practices for PNES in Namibia.

A total of 25 participants partook in this quantitative part of the study. Although most of the respondents were from Windhoek, responses were received from Swakopmund, Walvisbay, Otjiwarongo, Oshakati, Keetmanshoop and Okahandja. The largest proportion of respondents were aged between 51 and 60 years (45.83%), followed by 25 per cent aged between 41 and 50 years and 20.83 per cent between 31 and 40 years. Respondents were predominantly male (62.5%), with females making up 37.5 per cent of the responses. Specialities included 37.5 per cent general medicine, followed by 33.3 per cent psychology, 20.8 per cent psychotherapy, 16.7 per cent psychiatry and 12.5 per cent general neurology (see Figure 3.2).



*Figure 3.2.* Speciality distribution of HCPs who completed questionnaires on the current diagnostic and treatment practices for PNES in Namibia.

### **3.3.3 HCP perceptions and experiences regarding the management of ES.**

A total of 15 participants were recruited to participate in this qualitative phase of the study. The participants consisted of two neurologists, 12 GPs and one gynaecologist. Years in practice ranged from eight to 47 years (median = 20) and average age from 34 to 74 years (mean = 48.5). Twelve of the participants were male, while the remaining three were female. The participants consisted of six Black, two Mixed and seven White individuals (see Table 3.3).

Two of the GPs indicated a special interest in psychiatry and psychology, while some of the other GPs specified specialization in occupational health, aviation and travel medicine, and HIV medicine. Five of the HCPs practice in Rehoboth, a town 90 kilometres south of Windhoek. The population consists of small-scale farmers, artisans and people who commute to Windhoek on a daily basis for reasons of employment. The preferred language is Afrikaans, and most of the residents are of Mixed origin. Two of the participants practice in Okahandja, a town 70 km north of Windhoek. The population is more urban than Rehoboth, with many of the residents commuting to Windhoek on a daily basis. There is a big military base just outside of town. It is a gateway to the North and West of the country and houses many industries and factories, although not on the same scale as in Windhoek.

Table 3.3. *Demographic description of the HCPs who participated in interviews on their perceptions and experiences regarding management of ES.*

<i>Participant</i>	<i>Age</i>	<i>Gender</i>	<i>Race</i>	<i>Qualification</i>	<i>Years in practice</i>
<i>B1</i>	53	Female	White	General Practitioner	25
<i>B2</i>	61	Male	White	General Practitioner	31
<i>B3</i>	60	Male	White	General Practitioner	35
<i>B4</i>	43	Male	Black	General Practitioner	18
<i>B5</i>	50	Male	Mixed	General Practitioner	13
<i>B6</i>	39	Male	Black	General Practitioner	14
<i>B7</i>	42	Male	Black	General Practitioner	13
<i>B8</i>	46	Male	Mixed	General Practitioner	20
<i>B9</i>	49	Female	White	General Practitioner	23
<i>B10</i>	53	Male	White	General Practitioner	30
<i>B11</i>	74	Male	White	Gynaecologist	47
<i>B12</i>	36	Male	Black	Neurologist	13
<i>B13</i>	34	Male	White	General Practitioner	8
<i>B14</i>	47	Female	Black	General Practitioner	20
<i>B15</i>	41	Male	Black	Neurologist	17
	<b>Mean 48.5</b>	<b>M: 80%</b>	<b>6B;2M;7W</b>		<b>Median 20</b>

Participant code: B = Second set of interviews; 1 = Number of interview

### 3.3.4 Current diagnostic and treatment practices for ES in Namibia.

A total of 25 participants partook in this quantitative part of the study. Although most of the respondents were from Windhoek, responses were also received from Walvisbay, Oshakati, Rehoboth and Okahandja. Most respondents were aged between 41 and 50 years (40%), followed by 24 per cent aged between 31 and 40 years and 51 and 60 years, e per cent aged between 61 and 70 and four per cent between 71 and 80 years. Respondents were predominantly male (72%), with females making up 28 per cent of the responses. GPs made up the largest proportion of responses (84%), followed by 12 per cent general neurology and 8 per cent general/internal medicine.

### 3.3.5 THP perceptions of and experiences with the management of seizures.

A total of 11 participants were recruited to participate in this qualitative phase of the study. The participants included six healers that practice traditional medicine, one spiritualist, one diviner, one religious healer and two spiritualists that indicated divination and herbalism as part of their speciality. The ethnic origins of the participants were indicated as five Herero, two Oshivambo, two Mixed, one Damara>Nama and one Nyanja. Years in practice ranged from 8 to 51 years (median = 27) and average age from 30 to 73 years (mean = 55.6). Six of the participants were male, while the remaining five were female (see Table 3.4).

Table 3.4. *Demographic description of THPs who participated in interviews on their perceptions of and experiences with the management of seizures.*

<i>Participant</i>	<i>Age</i>	<i>Gender</i>	<i>Ethnicity</i>	<i>Type of healer</i>	<i>Years in practice</i>
<i>C1</i>	69	Female	Damara>Nama	Traditional	39
<i>C2</i>	72	Female	Oshivambo	Traditional	51
<i>C3</i>	59	Female	Afrikaans	Religious	7
<i>C4</i>	66	Female	Herero	Traditional	39
<i>C5</i>	73	Male	Oshivambo	Herbalist/Spiritualist	26
<i>C6</i>	42	Male	Herero	Spiritualist	21
<i>C7</i>	40	Male	Herero	Traditional	30
<i>C8</i>	46	Male	Herero	Traditional	27
<i>C9</i>	50	Male	Herero	Traditional	35
<i>C10</i>	30	Male	Nyanja	Diviner	8
<i>C11</i>	65	Female	Afrikaans	Spiritualist/Diviner	12
	<b>Mean 55.6</b>	<b>M: 55%</b>			<b>Median 27</b>

Participant Code: C = Third set of interviews; 1 = Number of interview

### 3.4. Data Collection Procedures for PNES

In an effort to select a sample of HCPs to participate in the PNES part of the study, I forwarded a request to the HPCNA for a list of service providers in Namibia. I was informed that such a list could be compiled, but that it would require some effort and time on their behalf. After several attempts to secure such a list, I reverted to the telephone directory to identify possible participants for the study. The Namibian telephone directory lists approximately 180 GP

entries, of which the majority included e-mail addresses. Obtaining information on specialists such as psychiatrists and neurologists proved much simpler due to their limited numbers.

Once the list of possible service providers had been compiled, I identified the participants who would be invited to participate in the qualitative and quantitative phases of the data collection process. Preference was given to specialists such as psychiatrists and neurologists. The remainder of the list comprised of GPs with specializations and finally psychologists with a particular interest in neuropsychology. Telephone directory listings for GPs indicated specific specialization areas such as family practitioner, occupational health, avionics, obstetrics and psychiatry. The Motor Vehicle Accident Fund (MVA) in Namibia makes use of psychologists in private practice to render services to patients who have been injured in motor vehicle accidents. The MVA provided a list of service providers (psychologists) who had service contracts with them. Psychologists who choose to consult for the MVA specialize in neuropsychology and trauma counselling and I opted to include them in the sample for this reason. The final list consisted of 100 candidates who were invited to complete the survey and 28 candidates who were invited to participate in the interview phase of the study. Data collection started during September 2015 and was completed during in 2016.

#### **3.4.1 HCPs' perceptions of and experiences with the management of PNES.**

Twenty-eight HCPs were invited to participate in the qualitative phase of the study. This included two neurologists, five psychiatrists, ten psychologists and 11 GPs. An e-mail including a short description of the purpose and relevance of the study and an invitation to participate was sent out. The following documentation was attached to the mail: (1) informed consent form (see Appendix B1), (2) biographical questionnaire (see Appendix B2) and (3) semi-structured interview questions (see Appendix B3). This was followed by a telephone call to ensure that the relevant documentation had been received and to enquire whether the HCP would be prepared to participate in the study. If the HCP agreed to take part in the study, a meeting was arranged at a time and place that suited the HCP. Participants were either met at their consulting rooms, their homes or at the researcher's office.

Semi-structured interviews were conducted with 15 participants. The total number of interviews ultimately depended on theoretical saturation, and by the fifteenth interview, themes started to repeated and no new information was emerging (Lincoln & Guba, 1985).

Before conducting the interview, the relevance and purpose of the study were explained to the HCP and questions regarding the research were answered. The HCP was then asked to read and sign the informed consent form (see Appendix B1) and to complete the biographical questionnaire that explored the HCPs' qualification, speciality, years in practice and location (see Appendix B2). The researcher asked the HCPs' permission to record the interview for the

transcription process. Once permission had been obtained from the HCP, the researcher commenced with the interview (see Appendix B3). The semi-structured interview consisted of broad, open-ended questions that were based on the ILAE PNES Task Force survey for HCPs. This survey was developed to explore the diagnostic and treatment practices of HCPs. It was adjusted to gather detailed information and personal opinion regarding the diagnosis and treatment practices used for PNES in Namibia. Participants were prompted to elaborate on their perceptions and experiences during the interview process.

The following questions were used to guide the interviews:

1. Tell me about your work with patients with PNES.
2. What are the complexities involved in making a diagnosis?
3. What are, in your experience, the main causes of PNES?
4. What are, in your opinion, the main challenges that healthcare professionals face when dealing with patients with PNES?
5. What makes it easier (or will make it easier) for you as a health provider to address patients with PNES?

Probing techniques were used during the interviews to obtain as much information as possible from each participant. Interviews lasted approximately 40 minutes. Each interview ended by thanking the HCP for their time and willingness to participate in the study. Participants were informed that a transcript of the interview would be e-mailed to their personal e-mail address to enable them to verify and correct any information.

### **3.4.2 Current diagnostic and treatment practices for PNES in Namibia.**

The ILAE PNES TF Survey for HCPs was used to collect quantitative data. The survey was developed by the ILAE PNES TF to gather information on diagnostic techniques and treatment practices used by HCPs in the management of PNES. The purpose of the survey is to collect data for descriptive purposes and it is therefore not standardized. The survey is available in the public domain and consists of 36 multi-item scales (see Appendix B5). The following five dimensions are measured: (a) professional role of the HCP and their exposure to PNES; (b) diagnostic service for patients with PNES; (c) management of PNES; (d) aetiological factors; and (e) problems accessing healthcare.

An e-mail with a description of the purpose and relevance of the study was sent to 82 GPs, three neurologists, five psychiatrists and ten psychologists (a total of 100 participants) in Namibia, requesting them to complete the survey. The official letter of invitation to HCPs (see Appendix B4) was attached to the mail that indicated the link to the electronic survey, which was created on Survey Monkey (see Appendix B6). The electronic survey included two sections that covered the informed consent section of the questionnaire (see Appendix B1). The informed

consent was divided across two sections in the electronic survey due to word limits in Survey Monkey. Participants were also given the option of printing and mailing the questionnaire if it could not be completed electronically.

Thirteen of the e-mails were undeliverable, and 25 responses were received from the remaining 87 invitations, a response rate of 28.74 per cent.

### **3.5. Data Collection Procedures for ES**

To select a sample of HCPs to participate in the ES part of the study, I returned to the original list that I compiled for the PNES part of the study. During the PNES part of the study, it became evident that GPs play a significant role in the diagnosis and treatment of seizures due to the lack of available specialists. Whereas I sought GPs with specializations in the PNES part of the study based on the demographics of previous studies performed on PNES, this seemed less crucial for the part of the study that would focus purely on seizures and specifically ES. Due to the nature of ES and its organic pathology, it was deemed less likely that patients would be diagnosed by mental healthcare practitioners. For this reason, psychologists and psychiatrists were not included in the ES part of the study. I subsequently reviewed the original list by updating some entries, adding some new ones and deleting the ones that were undeliverable or not applicable.

Once the list of possible service providers had been compiled, I identified the participants who would be invited to participate in the qualitative and quantitative phases of the data collection process for ES. Interview participants were identified by being accessible in and around the major towns in Namibia due to logistical and time constraints.

The final list consisted of 71 candidates who were invited to complete the survey and 20 candidates who were invited to participate in the interview phase of the study. Data collection started during May 2017 and was completed by August 2017.

#### **3.5.1 HCP perceptions of and experiences with the management of ES.**

Twenty HCPs were invited to participate in the qualitative phase of the ES part of the study. This included two neurologists, one gynaecologist and 17 GPs. I was given an opportunity to present the results of the PNES part of the study at a Continuous Professional Development (CPD) event for HCPs. The CPD event allowed me the opportunity to invite HCPs to participate in the ES part of the study. The event was attended by 95 people from various disciplines, of which approximately 20 were GPs. During this event, seven HCPs indicated their willingness to participate in interviews for the ES part of the study. These candidates were contacted telephonically to arrange a meeting at a time and place that suited them. In five cases, documentation packs were hand-delivered to their offices before the arranged date of the interview. The documentation included: (1) letter of invitation to HCP re ES (see Appendix (C1),

(2) informed consent form (see Appendix C2), (3) biographical questionnaire (see Appendix B2), (4) semi-structured interview questions (see Appendix C3) and (5) ES survey for HCPs (see Appendix C4). In two cases the HCPs practised in other towns and the information was e-mailed to the HCPs. The remaining 13 HCPs who had been identified as possible candidates for interviews, were first contacted telephonically to enquire whether they would consider participating in the study. In cases where the answer was favourable, the same procedure was followed as described above. Documentation packs were hand-delivered before the interview if the HCP was located in Windhoek and it was e-mailed if they were practising outside of Windhoek. All HCPs were contacted by telephone to ensure that the relevant documentation was received in good order and to confirm the appointment. All the HCPs were interviewed at their consulting rooms.

Ultimately, semi-structured interviews were conducted with 15 participants. The total number of interviews depended on data saturation, and by the fifteenth interview themes started repeating and no new information was emerging (Lincoln & Guba, 1985).

Before conducting the interview, the relevance and purpose of the study were explained to the HCP and questions regarding the research were answered. The HCP was then asked to read and sign the informed consent form (see Appendix C2) and to complete the biographical questionnaire that explored the HCP's qualification, speciality (if any), years in practice and location (see Appendix B2). Permission was requested from the HCP to record the interview for transcription purposes. Once permission had been obtained from the HCP, the researcher commenced with the interview (see Appendix C3). The semi-structured interview consisted of broad, open-ended questions that are based on the ES survey for HCPs, which was developed to explore the diagnostic and treatment practices of HCPs. I aimed to gather more detailed information and personal opinion regarding the diagnosis and treatment practices used for specifically ES in Namibia. Participants were prompted to elaborate on their perceptions and experiences during the interview process.

The following questions were used to guide the interviews:

1. Tell me about your work with patients with seizures.
2. What are the complexities involved in making a diagnosis and treating seizures?
3. What are the general attitudes/reactions when people are diagnosed with epilepsy?
4. What do you think is the role of THPs in the management of seizures?
5. What would you say one should focus on in a study of this nature?

Probing techniques were used during the interviews to obtain as much information as possible from each participant. Interviews lasted approximately 40 minutes. Each interview ended by thanking the HCP for their time and willingness to participate in the study. Participants

were informed that a transcript of the interview would be e-mailed to their personal e-mail address to enable them to verify and correct any information.

### **3.5.2 Current diagnostic and treatment practices for ES in Namibia.**

After enquiring from leading researchers in the field of PNES and ES, I was informed that the ILAE does not have a survey for ES that is similar to the ILAE PNES TF Survey for HCPs. After collaborating with my promoter, I decided to adapt the ILAE PNES TF Survey for epilepsy. The main structure of the survey was retained. However, it was shortened from 38 to 27 questions as HCPs felt that the PNES version was very long and sometimes overly complicated. Questions were further ratified to incorporate ES terminology and aetiology. A question regarding THPs was added in line with the research aims of the present study. In essence, the survey still aimed to gather information on diagnostic techniques and treatment practices used by HCPs in the management of seizures (see Appendix C4). The purpose of the questionnaire was to collect data for descriptive purposes and it is therefore not standardized. The original PNES survey is available in the public domain. The multi-item scales were retained and the questionnaire measures the following five dimensions: (a) the professional role of the HCP and their exposure to ES; (b) diagnostic services for patients with ES; (c) management of ES; (d) aetiological factors; and (e) problems accessing healthcare.

The first round of invitations was e-mailed to 43 GPs across the country and one neurologist. The mail included a description of the purpose and relevance of the study and explained how the HCP could access the electronic survey, which was created on Survey Monkey (see Appendix C5). The official letter of invitation to HCPs re ES (see Appendix C1) was attached to the mail and indicated the link to the electronic survey. The electronic survey included two sections that covered the informed consent section of the questionnaire (see Appendix C2). The informed consent was divided across two sections in the electronic survey due to word limits in Survey Monkey. Participants were also given the option of printing and mailing the questionnaire if it could not be completed electronically. Seven of the e-mails were undeliverable, and two responses were received from the remaining 36 invitations.

At the CPD event for HCPs, 15 questionnaires were distributed of which 11 were completed. Another 20 questionnaires were hand-delivered to various HCP practices across Windhoek, as well as Rehoboth and Okahandja, the two towns closest to Windhoek. Of these, 12 were completed, bringing the total to 71 questionnaires distributed and 25 completed, a response rate of 35.21 per cent.

### **3.5.3 THPs' perceptions of and experiences with the management of seizures.**

Finding THPs to participate in the semi-structured interview phase of the study proved challenging. THPs were not asked to complete the questionnaires as the survey focused on the

biomedical services available to seizure patients in Namibia and aimed to gather information on the healthcare infrastructure in the country. As a result of failure to establish contact with the two informal THP organizations, I had to resort to alternative measures to identify possible participants. It became evident from the interviews with the HCPs and some of my Oshivambo colleagues that the healers seem to be more active in the rural areas. This can be explained by the near absence of biomedical facilities in the rural regions as well as the prevailing cultural beliefs in the less populated areas of Namibia. Seeing that Windhoek is mainly urban, biomedical facilities are more accessible, and popular beliefs tend to be more westernized. Although traditional healers regularly advertise in local newspapers, I was sceptical to contact the advertisers, as the healer fraternity is sometimes fraught with impostors (Insight Namibia, 2006). Instead, I had to rely on my social and professional contacts in an attempt to identify possible participants. This proved both laborious and time-consuming.

The process of identifying THPs was truly a process of snowball sampling. The first lead on a healer came via an Oshivambo friend. This healer supplied a telephone number of one other healer, who was in turn able to supply me with a list of other healers and telephone numbers. Many of the numbers were unreachable, but some worked and I was able to arrange meetings with some of them. These healers again provided names of other THPs who I contacted with varying degrees of success. Some agreed to participate subsequent to a telephone call, others were sceptical and suspicious and appointments were often not kept or the THP could not be reached on the day of the appointment. Possible participants were invited telephonically and the purpose of the study was explained verbally.

Ultimately, of the 36 healers identified, 21 were telephonically contacted, appointments were scheduled with 16 and eventual interviews conducted with 11. If the THP agreed to take part in the study, a meeting was arranged at a time and place that suited the THP. All the participants were met at their homes. In some cases I was accompanied by a healer who had a good command of the English Language and who was able to assist in clarifying some of the terms used during the interviews. The total number of interviews ultimately depended on theoretical saturation, and by the eleventh interview, various themes started repeating and no new information was emerging (Lincoln & Guba, 1985).

Before conducting the interview, the relevance and purpose of the study were explained to the THP and questions regarding the research were answered. The THP was then asked to read and sign the informed consent form (see Appendix D1) and to complete the biographical questionnaire that explored the THP's qualification (if any), speciality, years in practice and location (see Appendix D2). Permission was requested from the THP to record the interview for purposes of transcription. Once permission had been obtained from the THP, the researcher commenced with the interview (see Appendix D3). The semi-structured interview consisted of

broad, open-ended questions that explored the diagnostic and treatment practices of THPs regarding seizures. It aimed to gather detailed information and personal opinion regarding the diagnosis and treatment practices used for seizures among THPs in Namibia. Participants were prompted to elaborate on their perceptions and experiences during the interview process.

The following questions were used to guide the interviews:

1. What do you classify as a seizure and what do you think are the possible causes?
2. How do you explain the seizures to the patient and what is their reaction?
3. How do you treat seizures? How successful is it?
4. What kind of contact do you have with western doctors or hospitals and do you think Western medicine can work for seizures?
5. In your opinion, what problems do people with seizures experience?

Probing techniques were used during the interviews to obtain as much information as possible from each participant. Interviews lasted 30 minutes in some cases and up to two hours or more in others. Each interview ended by thanking the THP for their time and willingness to participate in the study.

### **3.6. Quantitative Data Analysis**

The internet-based survey platform, Survey Monkey, was used to collect responses. Data from the Survey Monkey compilation software were reformatted as an MS Excel spreadsheet. Questionnaires where more than 50 per cent of the items were incomplete were excluded from the analyses. In preparation for analysis, the data were coded, entered and cleaned. The data were analysed using descriptive statistics. Frequencies and percentages were tabulated for the categorical variables. Continuous variables were reported as means and ranges. Findings were reported in the form of frequency distributions and percentages, as well as means and ranges, to summarize the current diagnostic and treatment regimens used by HCPs in Namibia.

Descriptive statistics were used to arrive at conclusions regarding the following aims and objectives:

1. the nature of the conventional diagnostic and treatment services available to patients suffering from seizures in Namibia;
2. post-diagnostic instructions to patients diagnosed with seizures; and
3. inter- and cross-referral practices amongst HCPs and THPs regarding seizure patients.

### **3.7. Qualitative Data Analysis**

Qualitative research methods can generate a deeper understanding of the intricacies of human behaviour, illness perceptions and therapeutic interventions (Johnson & Onwuegbuzie,

2004). The qualitative researcher uses the scientific method to construct a more comprehensive picture of reality through the discovery of how individuals think and feel about their environment (Thorne, 2000). This being said, the analysis of qualitative data can be one of the most complex stages of the research project (Thorne, 2000). A qualitative researcher must therefore take a critical and dynamic stance throughout the process of analysis to ensure that raw data are transformed into meaningful knowledge (Thorne, 2000).

The literature describes a variety of approaches to analyse qualitative data depending on how the researcher aims to sort, categorize, conceptualize, refine and interpret the research findings (Thorne, 2000). Some analytic approaches include narrative analysis, content analysis, thematic analysis, case survey, grounded theory and thematic networks (Attride-Sterling, 2001; Bazeley, 2009; Braun & Clarke, 2006; Dixon-Woods et al., 2005; Thorne, 2000). Although these approaches all describe various ways of analysing qualitative data, it varies in its strengths and weaknesses, its ability to deal with different forms of evidence and the nature of the questions for which it is most appropriate (Dixon-Woods et al., 2005; Thorne, 2000). Based on the aims and objectives of the present study, thematic analysis as described by Braun and Clarke (2006) was deemed the most suitable method to analyse the data from the semi-structured interviews conducted with HCPs and THPs.

**3.7.1 Thematic analysis.** Thematic analysis was used to analyse the qualitative data of the present study in an attempt to identify the perceptions and experiences of HCPs and THPs during the diagnosis and treatment of seizures. Braun and Clarke (2006) suggest that researchers should first master the process of thematic analysis, as it is a foundational method that provides core skills that can be applied to several other methods of qualitative analysis.

Thematic analysis is a set of procedures used to identify, analyse and report themes across a data set (Braun & Clarke, 2006). Towards this end, it gives the researcher the ability to produce a detailed and multifaceted description of the data without imposing boundaries regarding theoretical frameworks (Braun & Clarke, 2006). Thematic analysis is, therefore, a flexible and convenient research tool. It requires less theoretical knowledge than some of the other approaches, and it is not linked to a specific theoretical framework (Braun & Clarke, 2006).

This method is criticized for the same reasons that make it attractive for novice researchers. Critics argue that it is unclear what precisely thematic analysis involves, what the aims are and what procedures are necessary to achieve its purpose (Dixon-Woods et al., 2005). Another criticism levelled against thematic analysis is that the absence of an existing theoretical framework to guide analytical statements may reduce thematic analysis to simple descriptions without the necessary depth, purpose and interpretative authority required to analyse qualitative findings successfully (Braun & Clarke, 2006; Dixon-Woods et al., 2005; Pringle, Drummond,

McLafferty, & Hendry, 2011). Notwithstanding the criticisms levelled against thematic analysis, Braun and Clarke (2006) argue that a researcher can produce an insightful analysis that answers the research questions if a rigorous and deliberate thematic approach is applied. To achieve this, Braun and Clarke (2006) propose a set of clear guidelines for performing thematic analysis that includes six distinct phases of analysis. Thematic analysis was therefore deemed appropriate as an analytic methodology for this study, as the final aim was to identify themes and patterns in the data set that describe the frustrations and experiences of HCPs and THPs in the diagnosis and treatment of seizures.

**3.7.2 The steps of thematic analysis.** The six phases of analysis suggested by Braun and Clarke (2006) were used to analyse the qualitative data based on Bronfenbrenner's ecological systems approach (Bronfenbrenner, 1979). During the first phase of analysis, the researcher should become completely immersed in the data through a process of continually and actively rereading the data until initial patterns can be identified (Braun & Clarke, 2006). A transcription service transcribed the individual interviews with the HCPs and THPs due to time constraints and to facilitate cross checking of the content. Once the completed transcripts had been received, I listened to the original audio recordings while comparing it to the transcripts to make sure that it was an accurate representation of the original interview. This allowed me to become more familiar with the extent and scope of the content of the data. Rereading the transcripts a second time enabled me to start noting interesting features in the data, which formed the basis for subsequent phases of analysis.

Phase 2 of the data analysis commenced once the process of familiarization was completed satisfactorily. This phase entailed the creation of preliminary codes from the data based on aspects that the researcher found interesting (Braun & Clarke, 2006). I established a coding system based on features in the data that related to the research question and the aims and objectives of the study. First, I printed a hard copy of each transcript and using coloured pens to circle and mark interesting aspects of each specific interview. I then used Microsoft OneNote to group the marked portions of the data electronically under different pages in one section. The pieces of the interview relevant to a specific code were copied and pasted to the corresponding page. Each datum was referenced with the code of the original interviewee, and coloured highlighters were used to mark specific sections of interest for later use. Once this process had been completed, I was able to combine some pages and eliminate others to form a more coherent picture of the data.

Once the coding structure had been ratified and the different pieces of data collected, the third phase of analysis required that the focus moves to the broader level of identifying themes (Braun & Clarke, 2006). Themes are described as recurring patterns of meaning in the data set that provide answers to the research question (Braun & Clarke, 2006). The importance of a

theme is judged by its relevance to the research question and not simply by quantifiable measures, in other words not by how many times it appears in the data set (Braun & Clarke, 2006). Themes are populated by merging the different codes into potential topics and collating coded extracts according to these themes (Braun & Clarke, 2006). I based the selection of themes on my judgement regarding the relevance of the coded extracts to the perceptions and experiences of HCPs and THPs in the management of seizures. Searching for themes was facilitated by tabulating the different systems of the ecological systems approach (Bronfenbrenner, 1977), namely the microsystem, the mesosystem, the exosystem and the macrosystem. Thematic networks were used as an illustrative mind-mapping tool to organize themes according to the various systems (Attride-Sterling, 2001). By adding the different codes to the thematic network, I was able to identify patterns of repetition within the data set (Braun & Clarke, 2006). At the end of this phase, I was able to create an overall impression of the various themes, sub-themes and coded extracts according to the different systems.

Phase 4 required me to refine the themes identified during the previous phase by critically evaluating the relevance of the coded extracts to each theme and the data set in its entirety (Braun & Clarke, 2006). Through this evaluation process, it became apparent that certain themes were redundant some themes had to be combined to form a more coherent whole, while others could be divided into separate themes (Braun & Clarke, 2006). The reviewing and refining of themes were performed using two different levels of analysis (Braun & Clarke, 2006). The first level entailed a revision of the coded extracts to determine whether it forms a consistent pattern (Braun & Clarke, 2006). To achieve this, I reread the collected extracts and performed some restructuring by discarding and moving the coded extracts until I was satisfied that each theme captured the essence of the coded data (Braun & Clarke, 2006). The second level of analysis required me to review the various themes in relation to the entire data set to determine whether the final thematic network accurately represented the data (Braun & Clarke, 2006). Upon completion of the stage, I had a fairly clear understanding of the entire data set and how the various themes fit together to form a coherent narrative (Braun & Clarke, 2006).

At the start of Phase 5, I was satisfied that I had a representative thematic network of the data and could continue to refine and define the themes previously identified (Braun & Clarke, 2006). I had spent a fair amount of time during the Phase four on determining whether themes and coded extracts truly complemented each other and could therefore focus on the organization of the themes into a coherent whole during Phase 5. I then continued to create subthemes and wrote a detailed analysis of each theme (Braun & Clarke, 2006). After small adjustments, I was satisfied that I had captured the essence of the data in a clear, concise and organized manner. During the above five phases, I regularly engaged in discussions with my promoter to receive

guidance on the various processes and to explore emerging ideas, as well as to discuss areas of concern regarding the study.

Phase 6 required the writing of the report that would tell the complex story of the data in a convincing manner. By using vivid examples and extracts from the data, one should attempt to convince the reader of the merit and strength of the data analysis (Braun & Clarke, 2006). During this stage, I completed the final analysis of the data and wrote the report. The final report relates the story of the data in a logical, continuous and exciting way with enough evidence in the form of direct quotations to support the themes (Braun & Clarke, 2006). Towards this end, I endeavoured to apply the analytic narrative as an argument in an attempt to answer the research question and not merely as a description of the data (Braun & Clarke, 2006). The results of the study are presented according to the various systems of the ecological systems approach (Bronfenbrenner, 1977) and the main and subthemes that are identified as perceptions and specific experiences encountered by HCPs and THPs in the management of seizures. The final results are reported in Manuscripts one, three and four in this dissertation.

### **3.8. Maintaining Trustworthiness**

The worth of any research study is determined by the evaluation and criticism of peers, readers and fund reviewers (Krefting, 1991; Long & Johnson, 2000). However, the worthiness of qualitative research is often evaluated using criteria such as validity and reliability applicable to quantitative research (Long & Johnson, 2000). As an alternative, the concept of ‘trustworthiness’ is used by qualitative researchers to describe the virtues of a study outside of the parameters that are ordinarily used in quantitative research (Given & Saumure, 2008). Towards this end, Guba (1981) proposes four criteria that should be considered in a trustworthy study namely credibility, transferability, dependability and confirmability. This section discusses the criteria used to ensure trustworthiness in this study.

**3.8.1 Credibility.** Jensen (2008b, p. 3), defines credibility “as the methodological procedures and sources used to establish a sound level of congruence between participants’ expressions and the researcher’s interpretations of their expressions.” Credibility can therefore be described as the processes applied to ensure that the data present an accurate picture of the phenomenon studied (Given & Saumure, 2008; Shenton, 2004). In an effort to ensure that the data are represented fairly and truthfully, peer debriefing, peer examination and member checks were used (Long & Johnson, 2000; Shenton, 2004).

**Peer Debriefing.** Peer debriefing is described as collaborative sessions between the researcher and superiors that can act as a sounding board for ideas. Such sessions help the researcher to identify biases in thinking and to generate different perspectives on and explanations for the research project (Shenton, 2004). As part of the process of debriefing, I

regularly engaged in discussions with my promoter, not just to receive guidance at various stages of the project, but also to explore emerging ideas and areas of concern regarding the study.

**Peer Examination.** Peer examination allows for scrutiny of the research project by methodological experts so that they can comment on various aspects of the research plan, such as plausibility, the strength of arguments and overall research design (Krefting, 1991; Shenton, 2004). Before the commencement of data collection, the research proposal for the present study was reviewed by the Departmental Ethics Screening Committee (DESC) of the Department of Psychology at Stellenbosch University. Once the changes as suggested by the DESC had been effected, the research proposal was reviewed and approved by the Research Ethics Committee: Human Research (Humanities) of the University. After the submission of the manuscripts to peer-reviewed journals, I received invaluable input from the article reviewers for the article that was accepted for publication. This feedback from reviewers enabled me to improve and elucidate the findings of the study and was incorporated into the final article submission. The same process will be followed for those manuscripts that are still under review.

**Member Checks.** Member checks give participants the opportunity to verify the findings of the collected data to establish whether it is an accurate reflection of their viewpoint (Krefting, 1991; Long & Johnson, 2000; Shenton, 2004). Member checks were performed both during and after the interview process. During interviews, participants were requested to confirm whether my interpretation clearly and unambiguously reflected their own words. I asked some of the HCPs and THPs to verify a copy of their transcript and used this to clarify and correct some of the information that was unclear during the recording process. Emerging themes were discussed with some of the HCPs and THPs to verify certain patterns and the implications this may have for the results of the study.

**3.8.2 Transferability.** Transferability is the qualitative equivalent of generalizability, which is used in quantitative research to describe the degree to which findings from a study can be generalized to situations or contexts that fall outside the scope of the specific study (Jensen, 2008c; Merriam, 1995). The decision on whether the findings of a research project can be transferred to other settings depends on the consumer of the research and not solely on the researcher (Merriam, 1995). It is therefore the responsibility of the researcher to provide future researchers with as much information as possible regarding the study to enable them to make informed decisions about the transferability of the findings. I attempted to provide as much contextual information as possible about the research context, processes and participants to enable users to draw their own conclusions regarding the transferability of the findings (Morrow, 2005).

**3.8.3 Dependability.** Dependability is defined as the ability to replicate the study, yielding the same results, independent of maturation and historical effects (Shenton, 2004).

Complete and explicit explanations of the research methodology, analysis and interpretation of the data should be provided in order to achieve this (Krefting, 1991). The provision of adequate methodological information on research instruments and procedures used in the study should enable future researchers to arrive at similar explanations for the findings given similar conditions (Given & Saumure, 2008). Detailed descriptions of the context, research methodology, implementation and findings are provided in the dissertation to enable future researchers to repeat the study.

**3.8.4 Confirmability.** Confirmability is concerned with the degree to which the results of a study truly reflect the informants' perceptions and excludes the beliefs and biases of the researcher (Decrop, 1999; Jensen, 2008a). It is, therefore, important that the findings of the research reflect the perceptions of the participants and that they are not unduly influenced by any preconceived ideas of the researcher. Even though Morrow (2005) states that the researcher can never be entirely objective, I endeavoured to manage the influence of subjectivity through the processes of reflexivity and triangulation.

**Reflexivity.** Researcher reflexivity allows the researcher the opportunity to reflect on how personal experiences, subjective values, feelings, attitudes and worldviews may affect the research process (Long & Johnson, 2000; Morrow, 2005). In an effort to minimize the impact of researcher bias, I compiled a detailed profile for each HCP and THP that was interviewed (see Appendix G). In these profiles I reflected on the interviewing process by noting my impressions and some of the reactions observed in the participants. In the final chapter of this dissertation I reflect on my subjective feelings and how my background may have impacted on the research process. Given the fact that I am a middle-aged White female, raised according to Western beliefs and that I am currently practising in the field of psychology after years spent as a systems analyst, made me aware of my own preconceived ideas when interacting with the participants.

**Triangulation.** Triangulation implies looking at the research question from different angles by using multiple data sources, methods of data collection and analysis, theories or researchers to substantiate or illuminate the research problem (Decrop, 1999; Long & Johnson, 2000). The purpose of triangulation is to reduce the impact of researcher bias and the disadvantages that may occur as a result of using a single method, source or investigator (Decrop, 1999; Long & Johnson, 2000). For the purposes of this study, I used triangulation of data sources, method, theory and researchers. Triangulation of data sources implies the use of a diverse range of informants to maximize the understanding of the topic and to crosscheck the reliability of information derived from different participants (Krefting, 1991; Patton, 1999; Shenton, 2004). To accomplish triangulation of data sources, participants were drawn from various sectors of healthcare provision to increase diversity and to counter the effects of similar perceptions shared by a particular discipline.

Method triangulation “entails the use of multiple methods to study a single problem” (Decrop, 1999, p. 159). More reliable and dependable information is gathered when quantitative and qualitative data are combined to illuminate complementary aspects of the same research problem (Decrop, 1999; Patton, 1999). This form of triangulation was achieved by using data from questionnaires to detect practices underlying HCPs’ and THPs’ perceptions and experiences regarding seizures, while qualitative information in the form of semi-structured interviews was used to illuminate the quantitative data.

Theoretical triangulation involves incorporating ideas from different theoretical perspectives to interpret the same data (Decrop, 1999; Guion, 2002; Patton, 1999). Triangulation of theory is achieved by involving individuals from different disciplines or different status positions in the evaluation and interpretation of the data set (Guion, 2002). Different perspectives are garnered from various positions and disciplines, and if these perspectives converge, then validity is established (Guion, 2002). Therefore, to ensure triangulation of theory, I discussed emerging patterns with my promoter to elucidate and compare ideas from different disciplines and positions.

Researcher triangulation involves making use of various researchers to interpret and analyse the same data set (Decrop, 1999; Patton, 1999). Typically, researcher triangulation would be achieved by involving a research team consisting of colleagues in the same field of study using the same methods as originally applied by the investigator (Guion, 2002; Krefling, 1991). The researcher can achieve an important “check on selective perception and blind interpretive bias” by means of the comparison of the findings of more than one researcher during the analysis of the same data set (Patton, 1999, p. 1195). If evaluators arrive at similar conclusions regarding the findings of the study, the results of the study are confirmed (Guion, 2002). This form of triangulation was achieved by involving my promoter in the process of data analysis to ensure that we both agreed on the findings of the study and to identify any discrepancies in the final product.

### **3.9. Ethical Considerations**

This study received ethical approval from Stellenbosch University’s Research Ethics Committee: Human Research (Humanities) in December 2015, Proposal # SU-HSD-000546, National Health Research Ethics Committee (NHREC) registration number REC-050511-032 (see Appendix F1), and again in May 2017, Proposal # SU-HSD-004501, National Health Research Ethics Committee (NHREC) registration number REC-050411-032 (see Appendix F2). Participants who were invited to partake in the study were informed of the purpose of the study and its possible relevance to their field of work. Respondents were also informed that participation in the study is voluntary, free of charge and no remuneration was offered for partaking in the study.

Informed consent was obtained from each participant before the commencement of the study. Participants were assured that they could withdraw from the study at any point with no detrimental consequences to themselves, personally or professionally. Participants were informed that their identity would not be disclosed during the investigation, and that any identifiable information would be excluded from the final results. Participants are identified through a coded numbering system known to the researcher and promoter only. It was not the intention of this study to collect data on individual patients treated by healthcare providers and, therefore, no information regarding individuals is discussed.

The data gathered during the study were stored in a safe and secure environment for the duration of the study and will be appropriately destroyed after a period of five years.

The study was classified as low risk as the research was conducted on a largely uncontroversial topic through a survey and semi-structured interviews. The participants were adults (HCPs and THPs) and not considered to be a vulnerable research population. The research comprised of information that could be regarded as non-sensitive, such as opinion rather than personal information, and was collected anonymously through a mail survey and semi-structured interviews.

### **3.10. Summary**

This chapter provided a description of the research design and methodology employed in the present study. First, the rationale for the study was discussed, which outlined the need for investigating HCPs' and THPs' perceptions and experiences in diagnosing and treating seizures. The importance of this study in the context of a developing country was discussed by arguing that HCPs and THPs play a pivotal role in the management of a condition that can have crippling effects for people with seizures. This was followed by the research question and the aims and objectives, with a specific focus on the perceptions and experiences of HCPs and THPs. The rationale for using a concurrent mixed method design was presented next, followed by a description of the participants. Thereafter, sampling and data collection were discussed, as well as techniques used in qualitative data analysis and procedures that were applied in the thematic analysis. Finally, the steps to ensure trustworthiness and the ethical considerations were described. The next chapter presents the first manuscript of four that highlight the qualitative and quantitative results and the key findings of the study.

## Chapter 4: Manuscript 1

**Title:** Psychogenic nonepileptic seizures: Namibian healthcare providers' perceptions and frustrations

**Authors:** Anina du Toit & Chrisma Pretorius

**Brief Summary:** In this full research article, we report the findings from semi-structured interviews conducted with HCPs. This qualitative study focused on exploring the perceptions and frustrations of HCPs in the diagnosis and treatment of PNES in Namibia. Thematic analysis was used to identify the four main themes and related subthemes. It was evident from the analysis of the interviews that the perceptions and frustrations of HCPs centred on the areas of diagnosis, treatment, patients and awareness. The four systems of the ecological systems theory (Bronfenbrenner, 1977; 1979) were used to conceptualize the discussion of the subthemes and findings were linked to the existing literature on PNES. We also discuss the implications of the findings, limitations and suggestions for future research.

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## Psychogenic nonepileptic seizures: Namibian healthcare providers' perceptions and frustrations



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### ABSTRACT

**Purpose:** Most studies conducted on the diagnosis and treatment of psychogenic nonepileptic seizures (PNES) have been performed in developed countries with developing countries, such as Namibia, receiving less attention. This study aimed to contribute to the aims of The International League against Epilepsy Psychogenic Nonepileptic Seizure Task Force by investigating the perceptions and frustrations of healthcare providers (HCPs) in Namibia regarding the diagnosis and treatment of psychogenic nonepileptic seizures.

**Methods:** Semi-structured interviews were conducted with fifteen HCPs from the private healthcare sector in Namibia. Thematic analysis was used to analyse the semi-structured interviews in order to identify themes and subthemes within the data.

**Results:** Main themes centred on the areas of diagnosis, treatment, patients and awareness. It was found that HCPs' perceptions and frustrations were often related to the lack of knowledge and awareness regarding the disorder. Furthermore, the lack of access to specialized services and equipment contributed to HCPs' frustrations. Delays in the diagnosis of PNES added to HCPs' concerns regarding ineffective referral practices and the subsequent increase in healthcare costs. Although HCPs expressed the need for adequate training opportunities and increased awareness concerning the disorder, the lack of such opportunities and awareness campaigns were identified as possible problem areas.

**Conclusions:** It was evident from the findings that there are several gaps in how PNES are diagnosed and treated in Namibia. The unique challenges faced by a developing country such as Namibia were evident in some of the subthemes that highlighted the cultural differences in how PNES are conceptualized and treated.

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### 1. Introduction

Psychogenic nonepileptic seizures (PNES), resemble or mimics epileptic seizures (ES), but are in reality episodes of altered experience, sensation and movement, not as a result of abnormal electrical discharges in the brain, but rather underlying psychological stressors [1–3]. PNES is categorized as a conversion disorder, convulsion/seizure type by the Diagnostic and Statistical Manual of Mental Disorders [4]. At present, most of the studies conducted on the diagnosis and treatment of psychogenic nonepileptic seizures have been performed in developed countries with developing countries, such as Namibia, receiving less attention [5–8]. No official statistics or diagnostic and treatment guidelines on PNES or epilepsy are currently available in Namibia

(H. Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016).

Namibia is a country in South-western Africa, bordering on South Africa with a surface area of 824 116 square kilometres. It is a former German protectorate and mandate of South Africa from 1922 until 1966, after which it gained its independence in 1990.

The World Health Organization estimated the Namibian population at 2 459 000 in 2015 with a population density of 2.2 persons per square kilometre [9]. Despite its relatively low population and density, Namibia is culturally diverse with nine defined ethnic groups [10]. Thirteen national languages are recognized in Namibia with 87.8% of the population speaking ten indigenous languages and 11.2% speaking 3 Indo-European languages [10]. English is the official language of Namibia despite its status as a minority language [10].

The country is divided into 14 administrative regions, with the Khomas Region as the most central. The capital, Windhoek, is located in this region and acts as the judicial and administrative centre of the country. Windhoek is home to most of Namibia's

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manufacturing industries as well as business, educational, health-care and transport sectors [11]. Poverty levels are estimated at 29% of the population, the unemployment rate is 27.4% and HIV/AIDS prevalence is at 18.2% [12]. Neurological disease/disorders were rated as one of the top ten causes of death in outpatients in 2012 [12].

The general government expenditure on health as a percentage of total health expenditure is 60.4%, while 18.65% of the total health expenditure is covered by private health insurance and the remainder is out-of-pocket [9]. According to the World Health Organization, Namibia has 0.374 physicians per 1000 people, 12 psychiatric beds per 100 000 people, 4.78 CT units, 0.87 MRI units and 0.77 EEG monitors per million people [9]. No video-EEG monitors, which are known as the gold standard for diagnosing PNES, are available in the country.

The misdiagnosis of PNES as ES is common due to a lack of access to specialized equipment and expertise. Prolonged treatment with anti-epileptic drugs (AED) [7], associated stigma and loss of quality of life are compound consequences of misdiagnoses [13]. Patients who claim disability compensation on the basis of being declared medically unfit are costly both to the economy and the healthcare infrastructure. Improved understanding of the disorder by both patients and physicians may be achieved through accurate diagnosis and psychoeducation, which can potentially decrease the economic impact by between 69% and 97% [14].

In an attempt to raise awareness regarding PNES, the International League against Epilepsy (ILAE) PNES Task Force, initiated a worldwide campaign to collect information on the diagnosis and treatment of PNES. The aim of the current study was to identify the perceptions and frustrations of Namibian HCPs regarding the diagnosis and treatment of patients suffering from PNES. This study may not only contribute towards the goals of the ILAE PNES Task Force, but can also pave the way for future research on PNES in Namibia and other developing countries.

## 2. Methods

### 2.1. Participants

According to the Ministry of Health and Social Services Essential Indicators Database 2006–07 as reported in the WHO Regional Office for Africa Country Cooperation Strategy [15], Namibia has 557 medical practitioners which include dentists, psychologists and pharmacists. Namibia currently has two psychiatric wards, one in Windhoek and another in Oshakati with facilities that cater for approximately 200 patients in total [12]. The unit in Oshakati has access to one psychiatrist and one neurologist who is in private

practice. There are seven psychiatrists in Namibia in total, of which four are in private practice in Windhoek, two are employed by government and one is in private practice in Swakopmund. Namibia is being served by three neurologists, two of which are situated in Windhoek and the other in Oshakati in the far north of the country. Approximately 30 clinical psychologists practice privately in Windhoek and roughly the same number in the rest of the country, mainly situated in the coastal region. Mental Healthcare Services are predominantly provided in and around Windhoek for patients with access to medical aid funds [15].

Governing bodies for healthcare providers are limited to the Ministry of Health and Social Services (MoHSS), the Health Providers Council of Namibia (HPCNA), Namibia Medical Aid Fund Administrators (NAMAFA) and other private bodies. No organizations or societies exist for neurologists or psychiatrists specifically.

Purposeful sampling was used to identify potential participants from the available healthcare service providers' pool in Namibia. Recruitment took place between September 2015 and June 2016. The Health Research Ethics Committee at Stellenbosch University granted ethical approval for this study (protocol number: REC-050411-032). Eligibility for participation in the study was based on the speciality of the healthcare provider and excluded participants under the age of 21. HCPs were sourced from the private healthcare sector, taking into consideration that few specialists are employed by the public sector. Involving psychiatrists and neurologists in the study was vital considering the limited availability of specialists. General practitioners (GPs) were identified based on experience in treating epilepsy and PNES patients, years in practice and special interest in neurology and psychology.

### 2.2. Data collection

The Namibian telephone directory lists approximately 180 GP entries, of which the majority includes e-mail addresses and was used to identify potential participants. Telephone directory listings for GPs indicated specific specialization areas such as family practitioner, occupational health, avionics, obstetrics and psychiatry. Obtaining information on specialists such as psychiatrists and neurologists proved much simpler due to their limited numbers. A list of possible service providers was compiled while preference was given to specialists such as psychiatrists and neurologists. The remainder of the list comprised of GPs with specializations and finally psychologists with a special interest in neuropsychology.

Twenty-eight HCPs were invited to participate in the study. This included 2 neurologists, 5 psychiatrists, 10 psychologists and 11 GPs. An e-mail including a short description of the purpose and relevance of the study and an invitation to participate was sent out.

**Table 1**  
Questions that were used to guide the interviews.

Number	Questions
1	Tell me about your work with patients with PNES.
2	What procedures do you use to diagnose PNES? What about your confidence in making a diagnosis of PNES?
3	What are the complexities involved in making a diagnosis of PNES?
4	How is the diagnosis communicated to the patient?
5	What are your thoughts on the role of stigma in PNES?
6	How do patients understand/accept the diagnosis of PNES?
7	What are in your experience the main causes of PNES?
8	What role does secondary gain play in the diagnosis?
9	What is your opinion regarding referral of patients with PNES?
10	What would you consider the most effective treatment for PNES?
11	What are in your opinion the main challenges that healthcare professionals face when dealing with patients with PNES?
12	What will make it easier for you as a healthcare professional to deal with patients with PNES?
13	What is in your opinion the main challenges faced by patients with PNES?
14	What do you think can make it easier for patients with PNES?

The following documentation was attached to the mail: (1) informed consent form, (2) biographical questionnaire and (3) semi-structured interview questions. This was followed by a telephone call to ensure that the relevant documentation was received and to enquire whether the HCP would be prepared to participate in the study. If the HCP agreed to take part in the study, a meeting was arranged at a time and place that suited the HCP.

Prior to conducting the interview, the relevance and purpose of the study was explained to the HCP and questions regarding the study were answered. The HCP was then asked to read and sign the informed consent form and to complete the biographical questionnaire that explored the HCP's qualification, speciality, years in practice and location. Permission was requested from the HCP to record the interview for transcription purposes. Once permission had been obtained from the HCP, the researcher commenced with the interview. The semi-structured interview consisted of broad open-ended questions that were based on the ILAE PNES Task Force survey for HCPs which was developed to explore the diagnostic and treatment practices of HCPs. It aimed to gather more detailed information and personal opinion regarding the diagnosis and treatment practices used for PNES in Namibia. Participants were prompted to elaborate on their perceptions and frustrations experienced during this process. Probing techniques were used during the interviews to obtain as much information as possible from each participant. Interviews lasted between 30 and 40 min (Table 1).

### 2.3. Data analysis

Qualitative data from the semi-structured interviews were analysed using thematic analysis [16]. A mixed inductive approach, with themes identified from the data, combined with Bronfenbrenner's Ecological Systems Theory (EST) [17], was used to guide the data analysis. The EST was used to interpret and describe the perceptions and frustrations experienced by HCPs in a holistic manner by interpreting the ideas and meanings they have of PNES, themselves and their environments.

The individual interviews with the HCPs were transcribed by a transcription service due to time constraints, but also to ensure professionalism and crosschecking of content. Once the completed transcripts had been received, the original audio recordings were compared to the transcripts to ensure that it was an accurate representation of the original interview. This allowed A.d.T. an opportunity to become more familiar with the extent and scope of the data. Rereading the transcripts a second time started the process of noting interesting features in the data, which formed the basis for the next 5 phases of analysis (Table 2).

**Table 2**  
Stages of thematic analysis.

Stages	Action(s)
1	A.d.T. listened to audio recordings and compared it to transcriptions of the interviews. To become more familiar with the content, interviews were reread repeatedly.
2	Initial codes were generated using hard copies of the interview transcripts. Microsoft OneNote was then used to electronically group marked portions of the data under different pages in one section. It was a timeous process to combine some pages and eliminate others in order to form a coherent picture of the data.
3	Thematic networks were then used as an illustrative mind mapping tool in order to organize themes according to the various systems of the EST [18].
4	Reviewing and refining of themes by rereading collected extracts and comparing it to the entire data set in order to determine whether the final thematic network accurately represented the data. C.P. then reviewed the themes and coding structure to ensure a true reflection of the data set.
5	Refine and define the themes previously identified. Organized themes into a coherent whole and wrote a detailed analysis of each theme.
6	Writing the report, relating the story of the data in a logical, continuous and interesting way with enough evidence in the form of direct quotations to support the themes.

### 2.4. Maintaining trustworthiness

Credibility, transferability, dependability and confirmability were used to ensure trustworthiness in this study [19] (Table 3). In order to ensure that the data were represented fairly and truthfully, peer debriefing, peer examination and member checks were used [20,21]. Reflexivity and triangulation were used to ensure that the study truly reflect the informants' perceptions and excludes the beliefs and biases of the researcher [22,23].

## 3. Results

The participants consisted of three psychiatrists, two neurologists, six GPs, two clinical psychologists, one educational psychologist and one psychological counsellor. Semi-structured interviews were conducted with 15 participants. The total number of interviews ultimately depended on theoretical saturation and by the fifteenth interview, it was found that various themes had been repeatedly mentioned during the preceding interviews and that no new information was emerging [24].

Two of the GPs indicated specialization in psychiatry and psychology while other GPs specified specialization in allergies, occupational health and family medicine. The two clinical psychologists both specialize in forensic psychology and neuro-psychology. One of the psychiatrists specializes in child and adolescent psychiatry. Except for one participant who lives in Swakopmund, all others reside in Windhoek. (See Table 4 for demographic details).

Four main themes emerged as the most common areas in which HCPs expressed perceptions or frustrations regarding PNES. These themes included the areas of diagnosis, treatment, patients and awareness. Results are reported according to the main themes and are categorized into the micro-, meso-, exo- and macrosystems of the Ecological Systems Theory [17]. Thereafter, subthemes are reported as either perceptions or frustrations to provide a more complete understanding of the information. The subthemes are reported from the most immediate system surrounding the HCP to the most distant system with the vantage point that certain HCPs play a more prominent role during the diagnostic process, whereas others feature more strongly during the treatment phase when considering referral practices. Results from the thematic analysis are illustrated in Fig. 1 and Table 5.

### 3.1. Theme 1: Diagnosis

#### 3.1.1. Microsystem

**3.1.1.1. Use of basic diagnostic techniques.** Nine of the HCPs described the steps that they take to determine whether a patient suffers from PNES. This included clinical interviews where

**Table 3**  
Process of maintaining trustworthiness.

Process	Sub-process	Description of steps taken
Credibility	Peer debriefing	Regular discussions between authors at various stages of the project to explore emerging ideas as well as areas of concern regarding the study.
	Peer Examination	The research proposal for the study was screened by the Departmental Ethics Screening Committee and Research Ethics Committee: Human Research (Humanities) at Stellenbosch University prior to commencement of the study.
	Member Checks	Participants were given the opportunity to confirm the content of interviews, both during the interviews and after the data was transcribed.
	Transferability	Detailed contextual information was provided about the research context, processes and participants to enable users to draw their own conclusions regarding the transferability of the findings.
Dependability		Detailed descriptions of the context, research methodology, implementation and findings are provided to enable future researchers to repeat the study.
Confirmability	Reflexivity	In order to minimize the impact of researcher bias, a descriptive profile for each HCP was diarised in order to reflect on the interviewing process by noting own impressions and some of the reactions observed in HCPs.
	Triangulation	Multiple data sources were used from different sectors of healthcare provision. Method triangulation was used as this study is a subset of a larger study which used quantitative data in the form of questionnaires to illuminate qualitative data. Theoretical and researcher triangulation was achieved through the collaboration of the authors who compared findings from different disciplines and positions.

patients generally explain the seizures as “unusually prolonged”, “unusual manifestation” or “doesn't lose awareness but are unresponsive”. This is routinely followed by a physical examination, EEG and neuroimaging such as MRI or CT scan.

Five of the HCPs described the manifestation of PNES as distinctly different from epilepsy and they often seemed to make use of visual discrimination to distinguish between the two (Q1). Features such as “seizure duration”, “levels of consciousness” and “motor movements” were mentioned as some of the indicators used to distinguish PNES from ES.

**3.1.1.2. Use of diagnosis by elimination.** Five HCPs described the process of arriving at a definitive PNES diagnosis as “difficult” and often a matter of “elimination”. Once the possibility of comorbid epilepsy and all other possible explanations for the symptoms have been ruled out, HCPs seemed more willing to consider a diagnosis of PNES (Q2).

**3.1.1.3. Own lack of experience.** Seven of the HCPs expressed frustration at their own lack of experience in identifying and managing PNES. Concerns raised by HCPs include the fear of misdiagnosis or providing incorrect information to the patient or that they are “missing something else apart from the PNES”. HCPs admitted that it was more convenient to refer patients to specialists to perform the necessary investigations when they themselves were unsure or unable to establish a diagnosis, “It's

difficult to diagnose. I usually refer the people”. In two instances HCPs indicated that they refer patients to another HCP for a second opinion before the diagnosis is confirmed (Q3).

### 3.1.2. Mesosystem

**3.1.2.1. Delay in diagnosis.** Patients often seem to rotate amongst various HCPs, clinic visits, traditional and faith healers before a definitive diagnosis is reached. The subsequent delay in diagnosis and the effect this may have on the patient seem to be a cause of major concern for seven of the HCPs who also called it “costly” and “time consuming”.

**3.1.2.2. Affordability of healthcare.** HCPs describe PNES as an “expensive condition to have” due to the cost of specialists and the services needed to arrive at the diagnosis. Often patients find themselves in a position where they cannot afford specialized services (Q4–5).

### 3.1.3. Exosystem

**3.1.3.1. Other HCPs' lack of experience.** Five of the HCPs expressed frustration with the “lack of experience” and the “inability to differentiate between ES and PNES” displayed by some of their colleagues. The concern is that this may result in “inappropriate and delayed treatment” of the PNES patient (Q6).

**Table 4**  
Demographic information of participants.

P	Age	Gender	Race	Qualification	Years in Practice
1	39	M	Black	Neurologist	14
2	38	M	Black	Clinical Psychologist (PhD)	17
3	47	F	White	General Practitioner	21
4	57	M	White	General Practitioner	30
5	37	F	Mixed	Clinical Psychologist	10
6	47	F	White	Psychiatrist	24
7	37	F	White	Psychiatrist	13
8	57	M	White	General Practitioner	30
9	60	F	Black	General Practitioner	30
10	52	M	White	General Practitioner	25
11	28	F	Mixed	Psychological Counsellor	5
12	58	M	White	Psychiatrist	32
13	35	M	Black	Neurologist	10
14	53	M	White	General Practitioner	25
15	60	M	White	Educational Psychologist	34
	Mean 47	M: 60%	4B;9W;2M		Median 24

P=Participant, F=Female, M=Male.

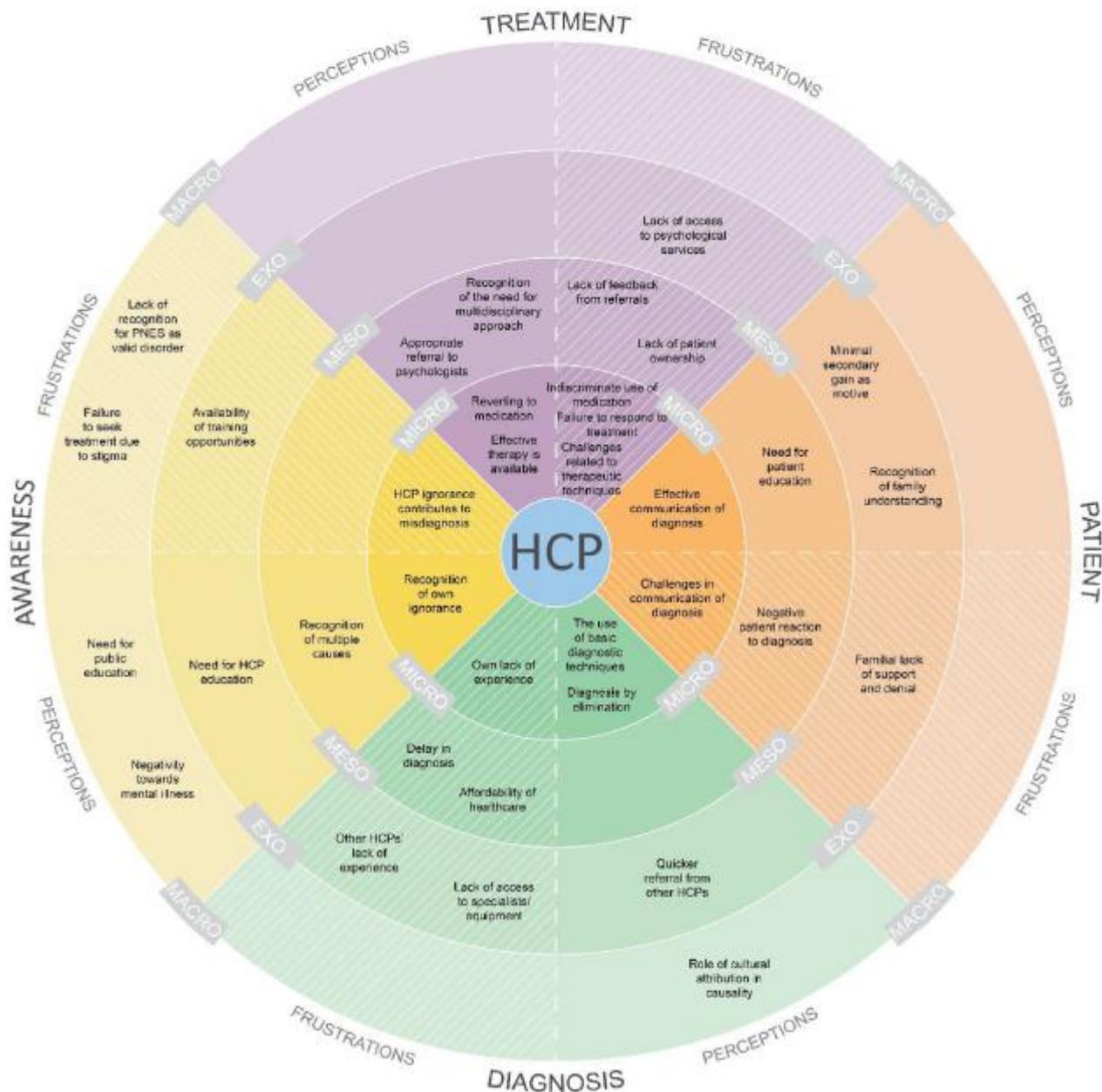


Fig. 1. A graphical illustration of the main themes and subthemes that were identified as perceptions and frustrations according to the different levels of the Ecological Systems Theory.

**3.1.3.2. Lack of access to specialists/equipment.** Eight HCPs expressed frustration with the lack of sufficiently specialized services in Namibia and the fact that there are only two EEG monitors in the country, of which one is Windhoek (Q7). Three HCPs mentioned the “*lack of video-EEG monitoring in Namibia*” as a frustration although one HCP mentioned that capturing the events on a mobile phone may assist diagnosis in the absence of video-EEG monitoring, “*You come here and you show me and nine out of ten times, most Neurologists look at that video and say okay that’s definitely this or that’s definitely that*”.

Three HCPs also expressed concern regarding the lack of “*specialized services*”, not only in and around the capital, but also in

the rural areas where access to healthcare is even more challenging (Q8). Three HCPs called EEG and video-EEG monitoring “*notoriously inaccurate*” in establishing a diagnosis of ES or PNES due to the inability to predict when a seizure will happen (Q9).

**3.1.3.3. Quicker referral from other HCPs.** There was an appeal from three of the HCPs that patients with PNES should be referred to the relevant specialist as quickly as possible and that casualty departments and GPs should “*know where to go with these kinds of patients*”.

**Table 5**  
Emergent main themes and illustrative quotes.

Main Theme	Illustrative quote
Diagnosis	<p>"A real clinical epileptic fit has got certain way and you know exactly that's what's happening. Psychogenic fit is different. You can see it clinically" (Q1)</p> <p>"If I confidently excluded everything else then I would know I'm comfortable to say that it is PNES" (Q2)</p> <p>"So most of my very difficult sort of cases is sent down to a doctor in Cape Town" (Q3)</p> <p>"This is a very expensive condition to have, because they've seen two or three different doctors already. And they've had extensive scans already. And if they do come here then they need mandatory neuroimaging and that really pushes up the cost of healthcare" (Q4)</p> <p>"There is a Neurologist who has to make the diagnosis. . . it's quite difficult because they have long waiting periods and the costs of accessing their services can be quite high and not all patients can actually afford to pay for those services" (Q5)</p> <p>"Lack of experience, there's a bit of fear, sort of over treat rather than under treat and that causes frustration because it delays appropriate treatment for patients" (Q6)</p> <p>" . . . the availability of EEG is next to almost nothing. I don't even want to estimate maybe one EEG per almost a million. Yes, so it's a problem because we have got how many Neurologists? Two in Windhoek, yes and there is, I think there is one in the North. And that's a huge challenge because those are the key people in dealing with and diagnosing PNES" (Q7)</p> <p>"But how are you going to make the diagnosis under a tree in Oshakati. You've not got EEG. You've not got CT scans. You've got nothing" (Q8)</p> <p>"We don't have a VEEG facility available here and also the difficulty with the video EEG is that you never know when a patient is going to actually get a true . . . or rather an attack" (Q9)</p> <p>" . . . they call pastors to come and pray because they say they are possessed with demons there now" (Q10)</p> <p>"Because epilepsy is treated you know dually. People end up at the hospitals but they do dual consultation, traditional healers, faith healers and the hospital because of attribution of causality" (Q11)</p>
Treatment	<p>"I would apply different approaches to different cultures. And of course depending on certain cultures some people feel like talking about their inner self is not an issue and they avoid that. And they are coming from a background of doctor patient of tell me what I should do. Which of course is not at all like cognitive behavioural. They want advice, so there are many cultures in Namibia where they feel they want directed advice" (Q12)</p> <p>"I have to say PNES is fairly common, and one thing is that a good number of patients will be started on AEDS when they have PNES and that is also a costly one where the disease won't get better and number two it's costly for the patient because they have to drink medication which needs money and also has side effects" (Q13)</p> <p>" . . . maybe they are frustrated or fatigued by this person because it's not maybe responding to whatever treatment that they had" (Q14)</p> <p>"It is a difficult condition to manage because it's quite unclear sometimes whether this is still a conversion disorder or if there have become some sort of malingering part to it or a secondary gain" (Q15)</p> <p>"I find that I refer to the psychologist but I might not get direct feedback from the psychologist to tell me you know what, the patient you sent this and this and this and we are trying to sort it this way" (Q16)</p> <p>"I think if we can just you know work together especially the psychologist the psychiatrist and the neurologist and then together with the patient and the family" (Q17)</p>
Patients	<p>"The skill is not what you convey to the patient in terms of the problem, the skill is how you convey that to the patient" (Q18)</p> <p>"People are confused because most of the times the patients I deal with in Namibia don't understand psychological and psychiatric conditions" (Q19)</p> <p>" . . . they would rather know this is what is wrong with me, they can actually pick it with a test and they can make it better but to have a condition that nobody really can place their finger on, I think must be quite daunting" (Q20)</p> <p>"Getting their family involved and explaining to them what's going on and how to help this person in dealing with this condition and not aggravating it or causing more stigma and shame" (Q21)</p>
Awareness	<p>"Many doctors confuse conversion symptoms with malingering and that tends to stigmatize this problem and it makes patients hesitant to seek help when they learn that this is in fact not true epilepsy" (Q22)</p> <p>"Some healthcare people don't know conversion disorders, diagnose it. It's very rare and these people usually end up somewhere finny" (Q23)</p> <p>" . . . it's a complex illness, it's not something that's standing alone. Very often there's co-morbid psychiatric problems, co-morbid personality problems, there's the social environment or relationships are not that well . . . that makes it's difficult, it's not a straightforward thing. It's a small part of a bigger picture" (Q24)</p> <p>" . . . when I want to admit them and I give the diagnosis to the medical aids they are told normally they won't admit this patient" (Q25)</p> <p>"I think there is definitely a big stigma especially in Namibia because it's easier for people to accept that there is something physically wrong with them than there being something mentally wrong with them or them not being able to cope with the demands of daily living" (Q26)</p>

### 3.1.4. Macrosystem

**3.1.4.1 Role of cultural attribution in causality.** According to two of the HCPs, the manifestation of "mass hysteria", especially in the North of the country, remain an interesting phenomenon and should be investigated in more detail (Q10). 'Mass hysteria' was attributed to cultural expressions of distress during challenging periods where whole groups of people present with seizure-like symptoms. HCPs stated that the "explanation is usually magical or spiritual and that they call pastors to come and pray". They continued to explain how the attribution of causality differs across cultures while one participant explained how epilepsy is approached in Zimbabwe through "dual consultation" with traditional and faith healers as well as medical doctors (Q11).

### 3.2. Theme 2: Treatment

#### 3.2.1. Microsystem

**3.2.1.1 Effective therapy is available.** All the HCPs agreed that patients can be treated successfully in Namibia. "CBT" and

"psychodynamic approaches" were stated as "the most effective approaches" to use during treatment, while "eye movement desensitization and reprogramming (EMDR)" and "trauma counselling" were also mentioned.

**3.2.1.2 Challenges related to therapeutic techniques.** Two HCPs mentioned the role of culture and how certain cultures perceive the self as "not an issue and they avoid it" during therapy, as an argument for the use of culturally appropriate techniques aimed at addressing inner conflict (Q12). They also stated that CBT may be perceived as "confrontational" in certain cultures and that even psychodynamic approaches may not be suitable due to the perception that talking about the inner self is not important and should be avoided.

**3.2.1.3 Reverting to medication.** Some HCPs supported the idea of pharmacological interventions and explained that "people have anxiety disorders, mood disorders and patients often have to be treated with antidepressants".

**3.2.1.4. Indiscriminate use of medication.** Patients who present with seizures are invariably prescribed AEDs or other medication in an attempt to manage their symptoms. Six HCPs indicated that this form of treatment is “premature” until a definitive diagnosis has been reached. HCPs expressed frustration at the “indiscriminate use of AEDs” and psychotropic medication in the treatment of PNES and voiced concern regarding the resultant increase in healthcare costs and the potentially dangerous side effects of these practices (Q13).

**3.2.1.5. Failure to respond to treatment.** Five of the HCPs admitted that it can sometimes be “difficult” and “time-consuming” to treat patients with PNES. Failure to respond to conventional treatment may result in doctor “fatigue or frustration” and questions can arise as to whether the patient is malingering or consciously faking the seizures (Q14–15).

### 3.2.2. Mesosystem

**3.2.2.1. Appropriate referral to psychologists.** Seven of the HCPs indicate that they often refer patients with PNES to psychologists and that psychotherapy plays “an important role in the treatment of this disorder”. Referral to other HCPs such as “occupational therapists, social workers, pastoral counsellors and physiotherapists” was also mentioned. However, some HCPs indicated that they are unaware of psychotherapy as a possible treatment option for PNES, “I never thought that sending a patient to a psychologist would help”.

**3.2.2.2. Lack of feedback from referrals.** Once an HCP has referred a patient to another HCP, the primary service provider expects some feedback with respect to what has been done. Lack of feedback from HCPs may result in poor patient management and was mentioned as a source of frustration by three HCPs (Q16).

**3.2.2.3. Recognition of the need for a multidisciplinary approach.** There was a call from five HCPs for a multidisciplinary approach in the treatment and management of PNES patients. Role differentiation amongst HCPs in terms of diagnosis and treatment creates a need for collaboration and information sharing regarding the management of patients with PNES (Q17).

**3.2.2.4. Lack of patient ownership.** According to six HCPs, patient management is often compromised due to a lack of coordination and communication between the different disciplines as “one specialist listens to the one thing and the other one does exactly the opposite thing”.

### 3.2.3. Exosystem

**3.2.3.1. Lack of access to psychological services.** Three HCPs mentioned that most patients “do not have access to private medical aids” and therefore rely on government facilities to provide mental health services. HCP experience frustration when patients “do not have adequate access to psychologists who can treat patients with PNES” or when “long waiting periods” interrupt the management of the disorder. A similar concern is raised regarding patients in rural areas.

## 3.3. Theme 3: Patients

### 3.3.1. Microsystem

**3.3.1.1. Effective communication of the diagnosis.** Nine HCPs described how they communicate the PNES diagnosis to the

patient. Specific terms such as “a combination of things”, “susceptible to stress or very anxious”, “underlying psychological causes” and “it’s not deliberate” are used to explain the diagnosis as sensitively and comprehensively as possible in order to facilitate understanding and compliance to treatment (Q18).

**3.3.1.2. Challenges in the communication of the diagnosis.** Four HCPs explained that communicating the diagnosis can sometimes be difficult, “it is probably the hardest part of all of this”. HCPs describe the reaction of patients as “surprised, confused and resistant depending on their insights”. Factors that contribute to the frustration of HCPs include patient sophistication and the confidence of the HCP in being able to impart the diagnosis successfully especially when “the doctor doesn’t understand what’s wrong with them and doesn’t communicate it to them”.

### 3.3.2. Mesosystem

**3.3.2.1. Need for patient education.** A lack of understanding of psychological and psychiatric conditions was mentioned as a barrier in the treatment of PNES patients (Q19). Three HCPs suggested that psychoeducation should form an integral part of the management of PNES in order to “educate them, explain it to them”.

**3.3.2.2. Negative patient reactions to the diagnosis of PNES.** Six HCPs voiced their frustrations with the way patients perceive the experience of being diagnosed with PNES and how patients react following the communication of the diagnosis (Q20). HCPs described patients as “fed-up”, “desperate”, “concerned” and “they come back and say it’s not true”.

### 3.3.3. Exosystem

**3.3.3.1. Minimal use of secondary gain as motive.** Ten of the HCPs indicated that although secondary gain may be used as a motive in faking seizures, this does not appear to happen very often. HCPs described the factors that may play a role in secondary gain as “avoiding responsibility”, “securing family support, malingering or some other ulterior motive”.

**3.3.3.2. Recognition of family understanding.** Four HCPs indicated that it is important to involve the family in the treatment of the PNES patient. Participants explained that incorrect perceptions can be addressed by providing information to the family in order to facilitate adequate support and understanding (Q21).

**3.3.3.3. Familial lack of support and denial.** Challenges encountered in dealing with the family of the PNES patient constituted the biggest frustration for eight of the HCPs in the exosystem. Suspicion that the “person is looking for attention or putting it on” and that the family is “getting irritated or attacking the patient” results in lack of support on the side of the family. Participants indicated that parents often “ignore it” and that “they send their children for therapy because then their hands are clean”.

## 3.4. Theme 4: Awareness

Knowledge and awareness of PNES as a conversion disorder permeates all the previous themes, subthemes and systems. This occasioned the inclusion of a separate theme that relates only to the topic of awareness to provide an overarching picture of the various perceptions of the disorder while simultaneously highlighting the lack of knowledge concerning PNES. The subthemes in this section can therefore be applied to all the systems in the model.

### 3.4.1. Microsystem

**3.4.1.1. Recognition of own ignorance.** Five HCPs described their own level of knowledge and ignorance regarding PNES as “it is new to me”, “to my mind it is real epilepsy” and “I have never considered it to be stress related”.

**3.4.1.2. HCP ignorance contributes to misdiagnosis.** Six of the HCPs raised the concern that ignorance on the side of other professionals may lead to misdiagnosis, stigmatization and failure to seek treatment (Q22–23). This contributed to HCPs not being “aware of this condition and some might be aware but don’t accept this as an illness”.

### 3.4.2. Mesosystem

**3.4.2.1. Recognition of multiple causes.** Two of the HCPs indicated that they have seen PNES more often in females than males, while two indicated the opposite. HCPs described the aetiological factors as “possible trauma”, “potential sexual abuse”, “inter-familial conflict”, “internal conflict” and various stressors and other comorbidities (Q24).

### 3.4.3. Exosystem

**3.4.3.1. Need for HCP education.** The need for increased awareness among and education of professionals involved in the diagnosis and treatment of PNES was highlighted by HCPs who stated that it is important to “create public awareness”, “create doctor sensitivity” and that it is a “wake up call of the specialities that we need in Namibia”.

**3.4.3.2. Availability of training opportunities.** There was a call from HCPs for professionals to be trained in the management of PNES, “we need more information, and we need more coaching, training in terms of this disorder”. However, training opportunities seldom exist in Namibia and “you have to go out of the country for training”.

### 3.4.4. Macrosystem

**3.4.4.1. Need for public education.** Seven HCPs suggested that public awareness regarding PNES should be increased in an effort to de-stigmatize the disorder and to provide support and acceptance to patients with PNES. Participants reported that “I don’t think they know that there can be a difference between real seizures and pseudo-seizures”. HCPs continued to state that patients need to be “accepted as being ill” and need to receive more “sympathy and support”.

**3.4.4.2. Lack of recognition for PNES as a valid disorder.** One HCP indicated that a medical aid refused to grant permission for a PNES patient to be admitted to hospital on the grounds that PNES is a functional disorder and is therefore not seen as a condition that requires hospitalization (Q25).

**3.4.4.3. Negativity towards mental illness.** Nine HCPs expressed the conviction that any psychological or neurological disorder is often viewed in a negative light and as such carry the burden of being stigmatized (Q26). According to HCPs, public manifestations of seizures may result in feelings of “shame and ridicule” for the patient and are “distressing for people to witness”.

**3.4.4.4. Failure to seek treatment due to stigma.** Four HCPs noted that stigma often prevents patients from seeking the necessary treatment for PNES and patients are often viewed as “crazy” or that there is something “mentally wrong” with them.

## 4. Discussion

The prominent role of GPs in the diagnosis and treatment of PNES, the strong reliance on exclusionary diagnostic techniques, cultural attributions in how the disorder is perceived and treated and lack of awareness and knowledge regarding the disorder are some of the unique subthemes that were identified in the study. This may be ascribed to the paucity of studies that focus exclusively on the subjective experiences of HCPs in a developing country such as Namibia.

Central to the discussion of the perceptions and frustrations experienced by HCPs is the lack of knowledge and awareness of PNES as a valid disorder. This specific theme and its related subthemes permeated all the other themes and systems described in this study. General lack of awareness and knowledge regarding PNES influenced the way in which the diagnosis of PNES is made, and in many instances not made. The resultant frustrations that stem from the lack of knowledge and awareness during diagnosis include unnecessary delays until a definitive diagnosis of PNES is reached due to lack of access to specialists, specialized equipment, financial resources, failure to recognize the role of cultural attribution in causality and delays in the effective and timely referral of patients to other HCPs. It is therefore evident that some HCPs, and especially GPs, may require more training to distinguish ES from PNES. One means to do so may be the implementation of continuous professional activities aimed at increasing the knowledge and awareness of PNES in both conventional and traditional medicine. Furthermore, through the development of standardized methods for referral it may be possible to decrease the time needed to arrive at a diagnosis which may also result in a reduction of healthcare costs.

The lack of awareness and knowledge of PNES also impacted on the theme of treatment with HCPs unknowingly prescribing AEDs notwithstanding the fact that it has been shown to be ineffective in the treatment of the disorder [25]. Lack of knowledge regarding effective treatment of the disorder also results in doctor fatigue and the resultant referral to other HCPs in the hope of finding a solution. Although CBT has been identified as an effective treatment modality for PNES [26], many HCPs fail to recognize the validity of this treatment approach due to a lack of knowledge and experience. Ineffective referral practices between HCPs responsible for the diagnosis and HCPs involved in the treatment of the disorder, once again result in frustration with a lack of feedback and coordination of care at its root. Again, increased awareness and training for HCPs and the introduction of a multidisciplinary approach to the treatment of the disorder may contribute to improved patient management.

In the patient theme, lack of knowledge and awareness extended to patients with the effective communication of the diagnosis being complicated by patient ignorance. Although HCPs demonstrated that they are well versed in the appropriate techniques required to communicate complicated diagnoses, challenges arose when the HCP did not possess sufficient confidence and knowledge to guide the PNES patient. This was further complicated by negative reactions from the patient and family when they failed to understand and grasp the psychological underpinnings of the disorder. It is therefore important for the family to understand the diagnosis in order to increase the likelihood of familial support and to decrease the possibility of using secondary gain as a motive for the seizures. The provision of adequate sources of information to both patients and family may enable them to better understand the disorder and may also increase the likelihood of treatment compliance [27].

Finally, awareness and knowledge of PNES determines HCPs’ perceptions regarding the disorder and a lack of such awareness and knowledge contributes to the frustrations. PNES often remains

misdiagnosed and untreated because HCPs do not possess the necessary knowledge and experience to successfully manage the process of diagnosis and treatment [28]. Although most HCPs acknowledge the underlying psychological causes for the disorder, stigma associated with mental and psychiatric disorders presents a barrier to the successful treatment of PNES [29]. Both public and patient awareness and knowledge regarding the disorder contributes to the prognosis and outcomes of PNES. The most salient theme throughout this study centred on lack of awareness and knowledge regarding PNES. This influenced all the other domains and should therefore remain the focus when designing and implementing interventions such as public awareness campaigns and training opportunities for HCPs. This study is the first of its kind to be conducted in Namibia and the findings from this study serves as a departure point for future research on this topic. These findings have highlighted the perceptions and frustrations and the circumstances in which HCPs diagnose and treat PNES and makes a valuable contribution to the existing knowledge about PNES.

### 5. Limitations

The sample consisted of HCPs in private practice and did not include professionals in full-time government employment although some of the specialists do consult for the government. A further limitation is that HCPs who participated in this study were predominantly located in Windhoek, although a small number of HCPs from other towns also participated. The sample may therefore not represent providers across the whole country.

Second, the pool of HCPs was not homogenous in terms of qualifications and areas of expertise. However, the service providers in the sample do share the commonality that they all diagnose or treat PNES, albeit through the use of different techniques and approaches. This may be ascribed to the lack of specialists in Namibia and the reliance on GPs to serve the majority of the population. Unfortunately this is a true reflection of the current situation in Namibia. The diversity of the group is further reflected in the extent of support received for each of the subthemes. HCPs expressed support for themes related to their area of expertise, such as either the diagnosis or treatment of PNES patients depending on their vantage point. This may explain why few of the themes were supported by the majority of the HCPs.

Finally, the results of the thematic analysis were only verified by four HCPs, who were also able to confirm the accuracy of their interview transcripts. Due to time constraints on the side of HCPs, it was not possible to verify the remaining transcripts. However, member checks were used during the interviews to clarify the information and to address any misunderstandings or inconsistencies.

### 6. Conclusions

The exploratory nature of the present study paves the way for future research of HCP experiences in developing countries such as Namibia. To understand the role of culture in the manifestation, explanation and treatment of PNES, we are currently conducting a study to explore the experiences and roles of traditional and faith healers and how this disorder is customarily perceived and treated in non-western cultures. The majority of people in Namibia reside in rural parts of the country, with limited access to specialized services and equipment. It is therefore not surprising that people with PNES may seek care from traditional healers who are more physically accessible to these patients and who offer greater cultural and conceptual familiarity. Lack of communication between traditional healers and physicians was mentioned as one of the key challenges to the provision of care to patients. Therefore, a study of this nature may address the knowledge gap

between traditional and conventional healthcare provision in an attempt to improve quality of care to PNES patients.

Future research may also focus on identifying solutions for standardized referral practices and transition of care amongst HCPs, especially in countries where there is a lack of specialists. Diagnostic delays and the ineffectual rotation of patients amongst various HCPs were indicated as a major source of frustration by respondents in the present study. It may therefore be important to identify the management pathways by which effective and timely delivery of care can be achieved.

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### Conflicts of interest

None.

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## Chapter 5: Manuscript 2

**Title:** Diagnostic and treatment practices for psychogenic nonepileptic and epileptic seizures in Namibia

**Authors:** Anina du Toit & Chrisma Pretorius

**Brief Summary:** In this full research article, we report the results from the ILAE PNES Taskforce survey for HCPs and the ES Survey for HCPs. The information from the surveys provides a description of the diagnostic techniques and practices used by HCPs in the management of medically explained and unexplained seizures. The purpose of the surveys was to gather data for descriptive purposes and the article therefore presents the information by means of descriptive statistics. Frequencies and percentages for the categorical variables are tabulated. Continuous variables are reported as means and ranges. Findings are reported in the form of frequency distributions and percentages, as well as means and ranges to summarize the current diagnostic and treatment regimens used by HCPs in Namibia. We also discuss the implications of the findings, limitations and suggestions for future research.

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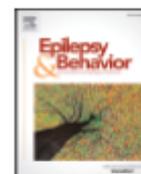
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## Diagnostic and treatment practices for psychogenic nonepileptic and epileptic seizures in Namibia

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### ABSTRACT

**Purpose:** Information about existing healthcare resources for the management of seizures in developing countries is lacking. These countries are often poorly equipped to deal with the immense burden of costs, mortality, stigma, seizure-related disability, and comorbidities presented by seizure disorders. This study aimed to contribute to the goals of the International League Against Epilepsy (ILAE) by investigating the resources available for patients with seizure in Namibia.

**Methods:** Two separate surveys on the diagnostic and treatment practices for epileptic seizures (ES) and psychogenic nonepileptic seizures (PNES) were administered to private healthcare practitioners (HCPs) in Namibia.

**Results:** The findings are based on 50 responses from HCPs involved in the management of seizures. The responses indicate that HCPs have less confidence in their ability to manage PNES than ES. Psychological/psychiatric assessments are seldom utilized. Although HCPs engage in face-to-face communication of diagnoses, they seldom refer patients to additional sources of information. Healthcare practitioners follow up patients with ES more regularly than those with PNES. Healthcare practitioners indicated their willingness to collaborate and recognize the role of traditional health practitioners (THPs) in a supportive capacity when it comes to the management of seizures. Financial constraints, limited availability of specialized equipment, and lack of knowledge and awareness regarding seizure disorders among both HCPs and patients were mentioned as major obstacles in accessing healthcare services.

**Conclusion:** The findings of this study add to the current literature by demonstrating some of the particular characteristics of HCPs from a lower middle-income African country regarding the diagnosis and treatment of PNES and ES.

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### 1. Introduction

The importance of investigating the diagnostic and treatment practices available for people with seizures cannot be overemphasized. Epilepsy affects the lives of between 65 and 70 million people all over the world, with between 80 and 90% found in developing countries [1,2]. Epilepsy is Sub-Saharan Africa's (SSA) most common, chronic and severe neurological disorder, and the costs, mortality, stigma, seizure-related disability, and comorbidities with which it comes are enormous [3,4]. One of biomedicine's greatest difficulties is successfully diagnosing and classifying seizure disorders. Epileptic seizures (ES) are often misdiagnosed, with false positives reported in up to 30% of patients [5–7]. Misdiagnosis can have grave consequences for patients, including the unwanted side effects of antiepileptic drugs (AEDs) as well as a negative impact on psychosocial functioning [8–10]. Misdiagnosis is often the consequence of a lack of knowledge about other conditions that look like ES, such as psychogenic nonepileptic seizures (PNES),

the over- and misinterpretation of electroencephalography (EEG) results, inefficient healthcare facilities, lack of training and experience among healthcare personnel, incomplete medical history taking, and lack of funds for specialist care [5,9,11,12].

The International League Against Epilepsy (ILAE) defines ES as “a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain” [13]. Psychogenic nonepileptic seizures resemble or mimic ES, but they are in fact episodes of altered experience, sensation, and movement, not as a result of abnormal electrical discharges in the brain, but rather underlying psychological stressors [14–16]. Conventionally, symptoms that arise as a result of organic pathology or physiological dysfunction (physical causes) are seen as “medically explained symptoms” (MES) whereas symptoms that are unexplained by organic disease is referred to as “medically unexplained symptoms” (MUS) [17–19]. According to the above two definitions, ES sort into the category of MES and PNES resort under MUS due to the medically unexplained nature of its symptoms, which instead arise as a result of psychological (psychiatric) causes. This distinction between MES and MUS for ES and PNES affects how the two conditions are usually managed by healthcare practitioners (HCPs). Treatment for MES seems relatively straightforward, with

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pharmacology in the form of AEDs being the preferred choice of action in the case of ES [1,20]. Various forms of psychotherapy are the most preferred and effective treatment for MUS, such as PNES. However, the misdiagnosis of PNES as ES is common, and it often leads to prolonged treatment with AEDs [21–25]. The debate surrounding the controversy of conversion disorders is also indicative of the perceptions described above, and although the psychiatric taxonomy recognizes its validity, many HCPs still consider it contrived and lacking a physical cause [26,27]. What is more, health professionals commonly misinterpreted the psychogenic origin of these seizures as a sign of deliberate fabrication. They then assume a negative attitude, and the patient fails to accept the diagnosis as a result [22].

Some countries are poorly equipped to deal with the immense economic, medical, and social burden that seizures bring, especially those that fall into the World Bank's classification of Low and Lower Middle Income (LMIC) based on gross national income per capita [11]. Sub-Saharan Africa, parts of Asia, Latin America, and the Pacific regions house most of these countries. They often battle with challenges such as inefficient healthcare systems, widespread poverty, and unevenly distributed material resources [11]. In addition, "The few efficient health care facilities that exist in these countries predominantly benefit people who reside in urban areas and those belonging to the economically advantaged section of society, and rarely benefit the poorer sections of the population who live mostly in rural areas" [11]. Namibia is no exception. Secondary and tertiary healthcare is more accessible to the affluent urban population of Namibia than to the rural poor [28].

Namibia has a dual healthcare system – one is public (state), and the other private. More than 60% of the total Namibian population of 2,459,000 rely on public healthcare provided by the Namibian government while 18.65% is covered by private health insurance and the remainder is out-of-pocket [29]. Namibia has 268 doctors and 66 specialists in full-time government employ to serve more than 1,700,000 uninsured Namibians while HCPs in the private sector mainly serve patients with private health insurance [30]. According to the World Health Organization (WHO), Namibia has 0.374 physicians per 1000 people; 12 psychiatric beds per 100,000 people; and 4.78 computerized tomography (CT) units, 0.87 magnetic resonance imaging (MRI) units, and 0.77 electroencephalography (EEG) monitors per 1,000,000 people [29]. No video-EEG (vEEG) monitors, which are known as the gold standard for diagnosing PNES, are available in the country, nor does the country have an epilepsy monitoring unit.

Most of the studies conducted on the diagnosis and treatment of PNES or ES have been performed in developed countries, with developing countries such as Namibia receiving less attention [25,31–33]. No official statistics or diagnostic and treatment guidelines on PNES or epilepsy can be found for Namibia (H. Riphagen, Personal communication, *Epilepsy Namibia*, 27 June 2016).

Even though epilepsy is the most common neurological condition worldwide, it involves more than just seizures, and patient concerns center on more everyday worries, such as questions about independent living, uncertainties about social and employment situations, and academic challenges [20]. The same is true for PNES, where associated stigma and loss of quality of life are additional consequences of misdiagnoses [34]. Given that it takes an estimated 7.2 years to reach a definitive diagnosis of PNES, seizures are costly, both to the economy and the healthcare infrastructure [35–37].

The successful management of seizures is, therefore, of extreme importance in developing countries with limited access to adequate healthcare infrastructure and manpower. As a result, it is crucial to determine the diagnostic and treatment options available for people with seizures and how the current infrastructure and skills base contend with ES and PNES. At the same time, health-seeking behavior in Africa is a multi-layered process grounded in a kaleidoscopic range of healing styles and treatment preferences [38,39]. It is no different in Namibia where patterns of utilization may include a variety of healthcare modalities and depend on perceived causes or the healthcare

treatment that is available [40–42]. The majority of people in Namibia reside in rural parts of the country with limited access to specialized services and equipment. It is therefore not surprising that people with seizures may seek care from traditional health practitioners (THPs) who are physically more accessible, who provide greater cultural and conceptual understanding, and whose explanatory model for seizures is possibly closer to those of the people they serve. Traditional medicine (TM) is defined by the WHO as "including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal, and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness" [43]. There is some cultural variation in traditional healing practices, but there are also many overlaps and shared practices among the various ethnic groups [40,41]. Traditional medicine in Namibia is offered by faith healers, diviners, fortune-tellers, spirit mediums, bone-setters, herbalists, and homeopaths [40]. African healing practices are traditionally transmitted from generation to generation through oral tradition and some form of apprenticeship [44]. As a result, these practices can be inconsistent, non-standardized, and undocumented [45]. African healing practices are also not universal, but rather personal and particular to an individual patient with treatment that focuses on the specific circumstances of the patient and the healer [45]. This is in stark contrast to the biomedical framework, which is based on scientific enquiry and where disease is seen as universal and treatment as similar across all modalities [46]. Most HCPs such as general practitioners (GPs), neurologists, and other specialists are formally trained in biomedicine at tertiary institutions based on the dominant model of disease in Western culture. In contrast, THPs seldom undergo formal training at tertiary institutions and instead rely on knowledge imparted through divination, apprenticeship, and tradition. The differences between the biomedical and traditional healthcare systems and the perception that biomedicine dominates in the field of healthcare often lead to distrust between HCPs and THPs [47,48].

The current study can contribute to the goals of the ILAE and the ILAE PNES Task Force by providing information on the diagnostic techniques and treatment modalities used in Namibia for the management of seizures.

## 2. Methods

### 2.1. Study design

This study formed part of a larger study that included a qualitative component. This article reports the findings of the quantitative part of the larger study and quantifies the approaches to the diagnosis and treatment of PNES and ES respectively. Purposeful sampling was used to identify participants from the available HCP pool in Namibia. According to the Ministry of Health and Social Services (MoHSS) Essential Indicators Database 2006–07 as reported in the WHO Regional Office for Africa Country Cooperation Strategy [49], Namibia is served by 557 medical practitioners that include GPs, dentists, psychologists, and pharmacists. Namibia is served by two state-owned and operated psychiatric wards that cater for approximately 200 patients in total. The psychiatric unit in Windhoek employs 4 psychiatrists while the unit in Oshakati, in the far north of the country, is served by one psychiatrist. There are three psychiatrists in private practice in Windhoek. Three neurologists practice in Namibia and render services to both state and private patients. Two of them are situated in Windhoek while the other one practices in Oshakati. Approximately 35 clinical psychologists practice privately in Windhoek and about 15 in other towns across the country. The psychiatric unit in Windhoek employs the services of 3 clinical psychologists.

The MoHSS, the Health Providers Council of Namibia (HPCNA), Namibia Medical Aid Fund Administrators (NAMAF), and other private bodies are tasked with regulating the activities of healthcare

professionals in Namibia. There are no societies or organizations that focus specifically on neurologists or psychiatrists in Namibia. Healthcare practitioners were mainly sourced from the private healthcare sector, taking into consideration that the public sector employs few specialists. Involving psychiatrists and neurologists in the study was vital considering the limited availability of specialists. General practitioners were identified based on experience in managing patients with seizures, years in practice, and special interest in neurology and psychology. The larger study originally focused on PNES and was later expanded to also focus on ES. For this reason, two separate questionnaires were administered on two separate occasions (2015–2016 for PNES and 2017 for ES). In the PNES part of the study, the sample included participants from the mental healthcare sector. The reason for including psychologists was motivated by the fact that treatment for PNES is largely performed by mental health professionals and it was, therefore, deemed necessary to include these HCPs in the PNES sample. With respect to the ES part of the study, psychologists were not included. The reason for this decision was that ES is largely seen as MES and is largely taken care of by GPs, neurologists, and in some cases psychiatrists. The samples for the PNES and ES parts of the study subsequently differed in its composition.

The ILAE PNES Task Force developed a questionnaire to gather information on the diagnostic techniques and treatment practices used by HCPs in the management of PNES. This questionnaire was administered to HCPs from September 2015 to June 2016.

Inquiries with the leading researchers in the field of PNES and ES revealed that the ILAE does not have a survey for ES similar to the ILAE PNES Task Force Survey for HCPs. It was, therefore, decided to adapt the PNES questionnaire to cater for ES. Questionnaires were administered between May 2017 and August 2017. Both questionnaires were administered in English as all participants were proficient in the language. Stellenbosch University's Research Ethics Committee: Human Research (Humanities) granted ethics approval for this study in December 2015 and May 2017 under National Health Research Ethics Committee registration numbers REC-050511-032 and REC-050411-032.

## 2.2. Questionnaire design

The ILAE PNES Task Force Survey for HCPs is available in the public domain and consists of 36 multi-item scales. The following five dimensions were measured: (a) professional role of the HCP and their exposure to PNES; (b) diagnostic services for patients with PNES; (c) management of PNES; (d) etiological factors; and (e) problems accessing healthcare.

The main structure of the PNES questionnaire was retained for the ES part of the study. However, it was shortened from 36 to 27 questions as HCPs felt that the PNES version was very long, it was overly complicated, and participants sometimes lacked the necessary information to complete percentage values. This prompted the decision to eliminate two questions relating to the percentage of state and private patients seen. In addition, none of the HCPs specialized in specific patient groups and needed to be fully trained and qualified to be considered for the study which eliminated two questions. Six questions that related to patient matters such as travel time for appointments, access to tests and treatments, waiting period for appointments, and how care is paid for were also deleted because of poor response rates in the PNES questionnaire. Questions were ratified to incorporate ES terminology and etiology. A question regarding THPs was added in line with the research aims of the larger study. The purpose of the questionnaires was to collect data for descriptive purposes, and it is, therefore, not standardized.

## 2.3. Data collection and preparation

The Internet-based survey platform, Survey Monkey, was used to collect responses. Data from the Survey Monkey compilation software

were reformatted as an MS Excel spreadsheet. Two of the PNES questionnaires, where more than 50% of the items were incomplete, were excluded from the analyses. All the ES questionnaires were fully completed.

For both the PNES and ES questionnaires, an e-mail including a description of the purpose and relevance of the study was sent to HCPs to invite them to complete the survey. An official letter of invitation was attached to the e-mail, indicating the link to the Survey Monkey questionnaire. The electronic survey included two sections that covered the informed consent section of the questionnaire. Participants were also given the option of printing, filling out and returning the questionnaire by e-mail if it could not be completed electronically.

## 2.4. Analysis plan

The data were analyzed using descriptive statistics. Frequencies and percentages were tabulated for the categorical variables. Continuous variables were reported as means and ranges. Findings were reported in the form of frequency distributions and percentages, as well as means and ranges, to summarize the current diagnostic and treatment regimen used for seizures in Namibia.

## 3. Results

### 3.1. Demographics

#### 3.1.1. PNES survey

The PNES survey invitation was e-mailed to 82 GPs, three neurologists, five psychiatrists, and ten psychologists (a total of 100 participants). Thirteen of the e-mails were undeliverable, and 25 responses were received from the remaining 87 invitations, a response rate of 28.74%. Although most of the respondents were from Windhoek, responses were also received from Swakopmund, Walvisbay, Otjiwarongo, Oshakati, Keetmanshoop, and Okahandja.

The majority of respondents were aged between 51 and 60 years (45.83%), followed by those aged between 41 and 50 years (25%), and those between 31 and 40 years (20.83%). Respondents were predominantly male (62.5%), with females making up 37.5% of the responses. Specialties included general medicine (37.5%), followed by psychology (33.3%), psychotherapy (20.8%), psychiatry (16.7%), and general neurology (12.5%).

#### 3.1.2. ES survey

The ES survey invitation was e-mailed to 43 GPs and one neurologist. Seven of the e-mails were undeliverable, and two responses were received from the remaining 36 invitations. At a Continuous Professional Development event for HCPs, 15 questionnaires were distributed, of which 11 were completed. Twenty questionnaires were hand-delivered to various HCP practices across Windhoek and two neighboring towns. Of these, 12 were completed, bringing the total to 71 questionnaires distributed and 25 completed, a response rate of 35.21%.

Most respondents were aged between 41 and 50 years (40%), followed by those aged between 31 and 40 years (24%), those aged between 51 and 60 years (24%), those aged between 61 and 70 (8%), and those aged between 71 and 80 years (4%). Respondents were predominantly male (72%), with females making up 28% of the responses. General practitioners made up the largest proportion of responses (84%), followed by general neurology (12%), and general/internal medicine (8%).

### 3.2. Professionals' role and exposure to seizures

Sixty-seven percent of the PNES survey participants stated that they diagnose PNES in 1–5 patients per year, compared with 56% of the ES survey respondents. The proportion of respondents who diagnosed a condition in 6–10 patients per year was 8% for PNES and

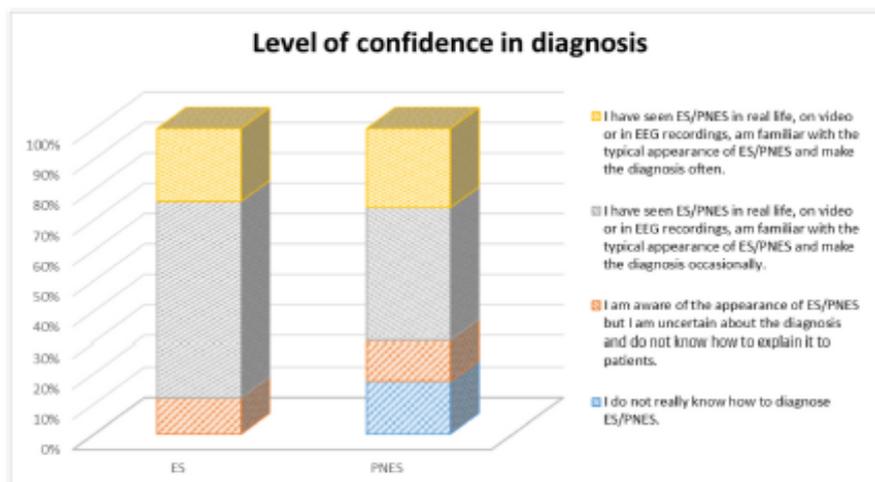


Fig. 1. Level of confidence to make a diagnosis of ES or PNES.

12% for ES, while the proportion of those who diagnose a condition in 11–20 patients per year was 4% for PNES and 8% for ES. Only the ES survey respondents indicated that they diagnosed ES in more than 20 patients per year (12%). Forty-eight percent of HCPs stated that they had 1–5 patients with PNES in their care compared with 32% who had 1–5 patients with ES in their care. Overall, the ES survey respondents tended to have more patients with ES in their care than the PNES survey participants.

When asked to describe their role in the management of PNES, participants most commonly stated that they refer to others when they suspect a diagnosis of PNES (59%), provide follow-up (54%), diagnose PNES (42%), and communicate the diagnosis (42%). Among the ES survey respondents, more involvement was reported, with 72% indicating that they prescribe medication for people with epilepsy (PWE), 60% providing follow-up, 56% diagnosing epilepsy, and 48% referring to others, while 48% recommending treatments for ES.

The ES survey participants expressed a higher level of confidence in their ability to diagnose ES (88%) compared with the PNES survey respondents who reported a level of confidence of 70%. The remaining 30% of HCPs in the PNES survey described themselves as “unfamiliar”

with a diagnosis of PNES or unable to distinguish between PNES and ES, compared with only 12% of the ES survey respondents (see Fig. 1).

Level of confidence about treatment reflected a similar pattern. Sixty-one percent of the PNES survey respondents regarded themselves as very familiar with PNES, able to explain the diagnosis, to propose treatment options, and to arrange treatment, compared with 80% of the ES survey participants. The percentage of respondents who declared themselves able to explain the diagnosis but unable to arrange or provide treatment was higher in the ES survey group (20%) than in the PNES survey group (17%). However, whereas 22% of the PNES survey participants indicated that they did not know how to explain PNES or how to treat the disorder, none of the ES survey respondents selected these responses (see Fig. 2).

### 3.3. Patient profile

The majority of the PNES survey group reported that they see PNES more often in women than in men (62%). Nineteen percent of the PNES survey respondents indicated that they see the condition in as many women as in men compared with the bulk of the ES survey

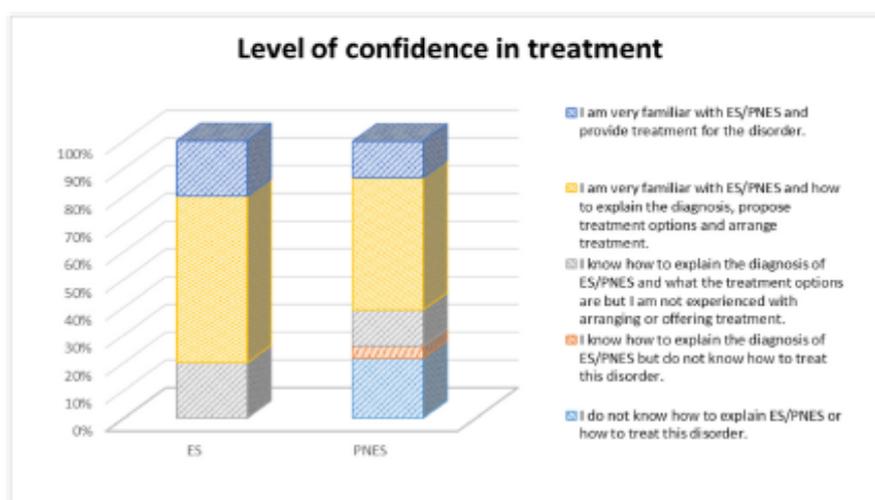


Fig. 2. Level of confidence to treat ES or PNES.

group who indicated that they see ES in as many women as in men (64%). Twenty-four percent of HCPs indicated that their patients receive state disability benefits because of their PNES, compared with 72% of the ES survey respondents.

### 3.4. Diagnostic methods

Ten of 24 HCPs in the PNES survey (42%) stated that they “personally diagnose PNES”. In this group, 44% of the GPs, 100% of the neurologists, 22% of the psychologists, and 33% of the psychiatrists endorsed this statement. In the ES survey group, 56% of the HCPs indicated that they “personally diagnose ES”, which included both the neurologists and 55% of the GPs.

Responses were similar between the two groups as far as the access to diagnostic tests is concerned. More than 70% of both the ES and PNES survey respondents indicated that routine EEGs are available for them (ES: 76%, PNES: 74%). Other tests that are available include routine electrocardiography (ECG) (ES: 76%, PNES: 63%), MRI of the head (ES: 68%, PNES: 74%), CT scans (ES: 64%, PNES: 79%), and neuropsychological testing (ES: 24%, PNES: 68%). Five percent of the PNES survey participants indicated that they have access to routine EEG with video (vEEG), compared with 4% of the ES survey respondents. Furthermore, HCPs’ mean estimate of the proportion of patients whose diagnosis of PNES was supported by recording of a typical event with vEEG was 2%, compared with 12% of patients whose ES diagnosis was supported by an EEG recording (see Fig. 3).

### 3.5. Psychological assessment

Although a large proportion (46%) of the PNES survey respondents described themselves as well informed about a range of psychotherapeutic approaches and how these could help patients with PNES, only 4% of the ES survey participants chose this response. Fifty percent of

the PNES survey respondents compared with 80% of the HCPs in the ES survey indicated that they are familiar with psychotherapy, but not specifically in relation to PNES or ES. Four percent of the PNES survey group did not know anything about psychotherapy, versus 16% in the ES survey group.

When asked how frequently patients are offered some form of psychological or psychiatric assessment, HCPs in the PNES survey stated that 55% of patients would “always” undergo a psychological assessment, 33% would undergo a psychiatric or neuropsychiatric evaluation, 30% would undergo a psychotherapeutic assessment, and 25% would undergo neuropsychological testing. However, the ES survey respondents indicated that only 4% of patients would “always” undergo a psychotherapeutic assessment, and the same percentage would undergo a psychiatric or neuropsychiatric evaluation (see Fig. 4).

According to respondents, psychotherapy is available for patients with a private medical aid (ES: 92%, PNES: 100%) and for publicly insured patients (ES: 32%, PNES: 52%).

### 3.6. Communication of the diagnosis

In the event of PNES, the survey results indicate that the diagnosis is most commonly communicated by the neurologist (64%), whereas the family doctor more commonly communicates the diagnosis in the case of ES (72%). When asked how the diagnosis of PNES or ES is communicated to the patient, results were very similar between the two groups. Healthcare practitioners stated that they provide a face-to-face explanation to the patient (ES: 92%, PNES: 95%), and 58% of the PNES survey respondents review the diagnosis with the patient’s family, compared to 60% of the ES survey respondents.

In their explanation of PNES, HCPs most commonly said that the causes of PNES are complicated and that there may be predisposing factors, factors that first triggered attacks, and factors that sustain the problem (65%). Other explanations included the following: the patient

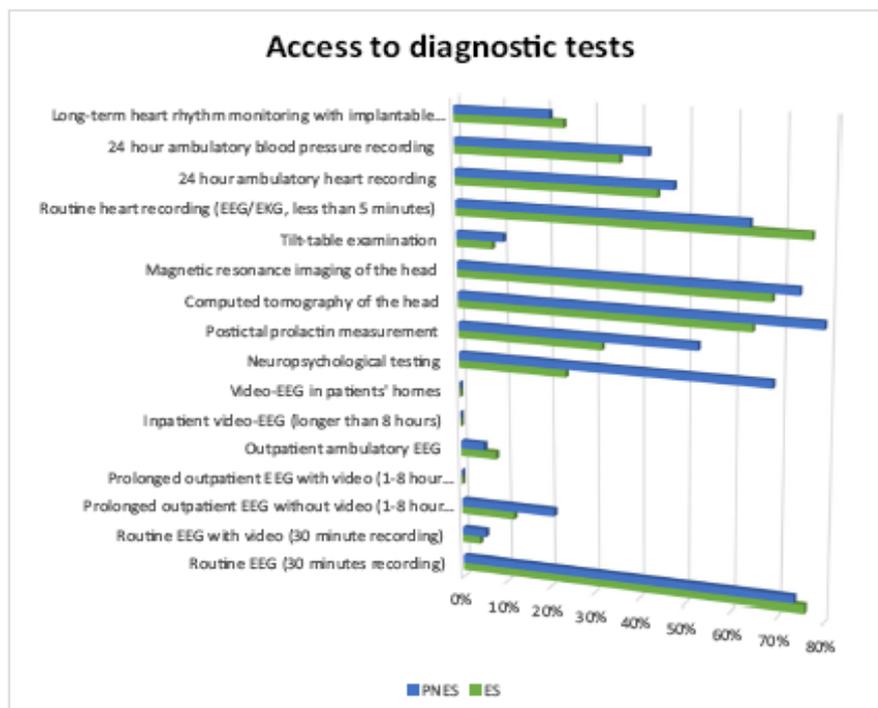


Fig. 3. Access to diagnostic tests for PNES and ES.

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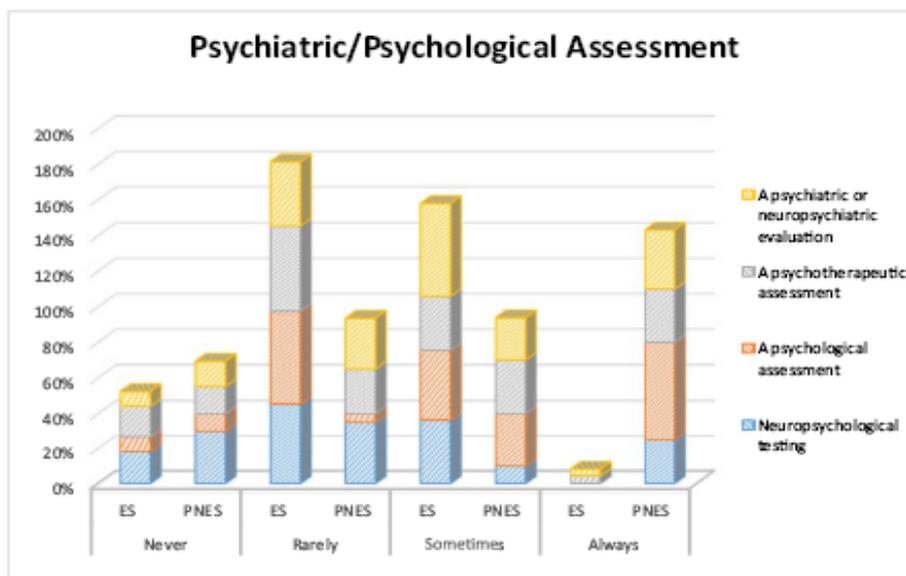


Fig. 4. Frequency of psychiatric or psychological assessment.

does not deliberately produce PNES (57%); PNES may be a result of past trauma or ongoing conflicts (52%); and PNES are seizures that can improve with psychotherapy (52%).

In the case of ES, most HCPs commonly said that the events are caused by electrical discharges in the brain (88%); that AEDs do work for epilepsy (80%); that AEDs may have side effects that have to be monitored regularly (76%); and that the causes of epilepsy are complicated and that there may be predisposing factors, factors that first started attacks, and factors that maintain the problem (60%).

### 3.7. Follow-up, treatment, and referral

Fifty-four percent of all PNES survey respondents stated that they provide follow-up for patients with PNES. General practitioners were least likely to provide follow-up (38%), with neurologists and psychiatrists providing follow-up in 100% of cases. All the psychiatrists and 67% of psychologists in the study provide treatment for patients with PNES. Healthcare practitioners estimated that they invite 59% of the patients with PNES to come back for at least one follow-up visit after the diagnosis had been communicated to them. The three main reasons given for providing follow-up after the communication of the diagnosis were as follows: as a rule, all patients with PNES are offered at least one follow-up appointment after the explanation of the diagnosis (48%); patients whose test results show the presence of additional mental health problems are invited for a follow-up visit (48%); or patients for whom medication was prescribed are invited for a follow-up visit (43%).

In the ES survey group, 80% of the HCPs follow up patients who administer AEDs, and 72% follow up patients when they prescribed other medication. Fifty-two percent of the HCPs in this group will also follow up patients whose seizures have stopped but could return, and 44% will follow up a patient who continues to doubt the diagnosis.

When asked about the most effective treatment for PNES, the majority of HCPs stated that individual psychotherapy is the most effective treatment for PNES (82%), followed by antidepressant drugs (9%). This question offered respondents the opportunity to mention treatments not included in the list. Nine percent of HCPs proposed psychoeducation and family therapy as the most effective treatment for PNES. Healthcare practitioners estimated the percentage of patients with PNES who will be offered at least one appointment for psychological treatment (including those who will fail to attend) at 55%.

All the respondents indicated that the most effective treatment for ES is AEDs, followed by individual psychological treatment (32%), benzodiazepines (24%), group psychotherapy (16%), and antipsychotic drugs (16%). An additional question that only appeared in the ES questionnaire gauged the perceptions of HCPs regarding the role of THPs in the management of seizures. Sixty-one percent of the HCPs agreed that THPs can play a supportive role in the treatment of seizures and that there should be more collaboration between HCPs and THPs (43%). A further 67% agreed that some patients with seizure prefer to be treated by THPs and concurred that culture plays a role in the manifestation of seizures (33%). However, 17% of HCPs strongly agreed that they will never refer a patient to a THP, and 44% strongly disagreed that THPs can treat seizures (see Fig. 5).

### 3.8. Etiological factors

The most common factors recognized as etiologically relevant for PNES in Namibia are family conflict/pressures (58%), anxiety (55%), accumulated life stress (48%), depression (41%), and childhood emotional/physical abuse (38%). Participants also considered personality disorders (35%), childhood sexual abuse (34%), and childhood emotional/physical neglect (34%) as likely etiological factors.

Causes that most often lead to the development of ES were stated as head trauma (76%), progressive brain disease (52%), other medical problems (50%), alcohol abuse (48%), congenital birth defects (48%), and genetic factors (39%).

### 3.9. Barriers to healthcare

The most commonly identified problems with regard to access to the diagnosis and treatment of PNES include the lack of access to information resources about PNES (48%), lack of financial means for an appointment with a seizure expert (48%), lack of general awareness of PNES (45%), lack of accessible HCPs who know about PNES (41%), and lack of money for psychotherapy (40%). Interestingly, the stigma associated with PNES is seen as the least common barrier to its diagnosis and treatment (13%) (see Fig. 6).

In the case of ES, difficulties that most often contribute to a lack of access to diagnosis and treatment were cited as a lack of money for an appointment with a seizure expert (63%), a lack of money for tests (48%),



Fig. 5. Role of THPs in the management of seizures.

a lack of money for an appointment with a nonspecialist physician (38%), a lack of access to information resources about epilepsy (38%), and problems with travel/geographic access to HCPs (33%) (see Fig. 6).

#### 4. Discussion

Namibia does not have official statistics or diagnostic and treatment guidelines for PNES or ES (H. Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016). This, combined with the goals of the ILAE and ILAE PNES Task Force to gather information on diagnostic techniques and treatment modalities for the management of seizures, prompted the need for the present study in Namibia. We have previously described the perceptions and frustrations of HCPs during the diagnosis and treatment of patients with PNES [50]. This survey data complement the findings of the previous qualitative study. The PNES findings of this study can be compared with a worldwide study [51] and studies conducted in the USA, Chile, UK, and Brazil that investigated

existing healthcare infrastructure and strategic health practices used for PNES management [52–55]. Findings for ES can be equated to studies that included information on epilepsy care in developing countries [56,57]. Comparisons can, therefore, be made between the findings of this study and those that examined conditions in other countries insofar as standard medical care for seizures is concerned.

##### 4.1. Expertise of healthcare professionals

It seems that PNES is diagnosed less frequently in Namibia than in Brazil, Chile, the UK, and the USA. Frequency of making the diagnosis of PNES in Brazil was reported as 3.3 diagnoses per month compared with a median of 2 new diagnoses per month in the UK, a mean of 1.3 in Chile, and 6.5 in the USA [52–54]. In the current study, 67% of HCPs indicated that they make the diagnosis of PNES in 1 to 5 patients per year, whereas 8% stated that they make the diagnosis of PNES in 6 to 10 patients per year. National income appears to play a role in

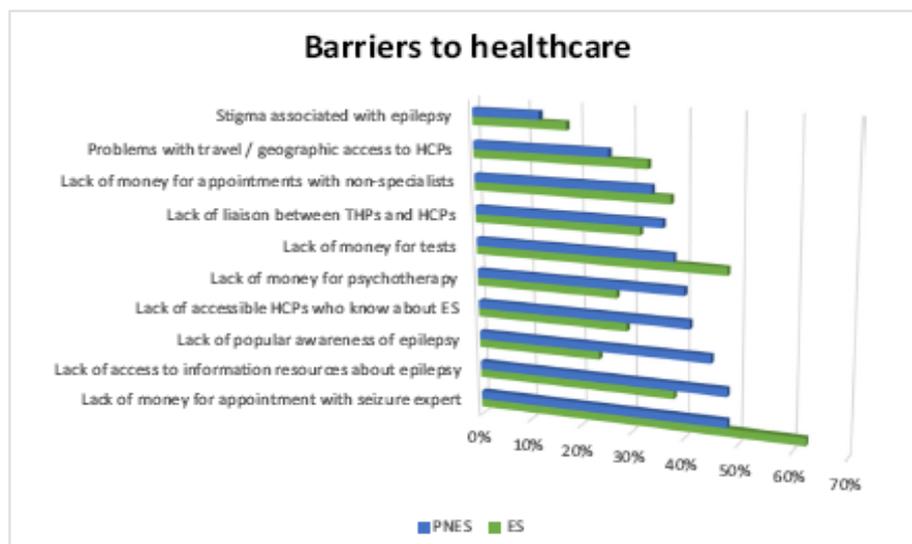


Fig. 6. Barriers to the diagnosis and treatment of PNES and ES.

diagnostic confidence with Namibian HCPs' confidence levels in diagnosing PNES ranging between those of practitioners in low-income (LI) and middle-income (MI) countries [51].

According to our surveys, HCPs reported a higher level of confidence in making an ES diagnosis compared with a diagnosis of PNES. A similar pattern was observed regarding the treatment of ES, with HCPs indicating that they feel more confident to treat ES than PNES. This was also reflected in the number of patients whose condition had been diagnosed and who are currently in their care, with the number of patients with ES far exceeding the number of those with PNES. This may be ascribed to the relatively unknown nature of PNES, the lack of experience among HCPs in being able to differentiate between PNES and ES, and a lack of access to specialists and monitoring equipment that can confirm the diagnosis [50].

#### 4.2. Diagnostic methods

Survey responses were similar when it came to the availability of specialized equipment and services in Namibia. On average, 75% of HCPs indicated that they have access to EEG monitoring, which is similar to the situation in Brazil, although much lower than in Chile, the UK, and the USA [52–54]. This is in line with findings from a worldwide study that established a relationship between availability of diagnostic tests and national income [51]. The lack of access to EEG monitoring can be ascribed to the fact that Namibia currently only has three EEG monitors, all of which belong to private practitioners, one in the north of the country and the other two in Windhoek. Namibia does not currently have a vEEG monitor or epilepsy monitoring unit [30]. This can also explain why only 2% of patients' PNES diagnoses are confirmed by vEEG, compared with 12% of ES diagnoses confirmed by EEG. This highlights the need to implement diagnostic strategies independent of specialized tests that can aid HCPs in establishing a diagnosis based on a description of the seizures, the patient's history, and eyewitness accounts [25].

#### 4.3. Psychological assessment

Although respondents from both groups indicated that they are reasonably informed about psychological/psychiatric evaluations, these types of assessments seem severely underutilized. In the case of PNES, only about half of patients are regularly referred for psychological/psychiatric assessment. Namibian respondents indicated a referral rate of no more than 55% compared with the UK (58%) and Brazilian respondents who reported that they refer patients with PNES to psychologists/psychiatrists in 78% of cases [53,54]. Worldwide, the Namibian referral rate for these assessments correspond to LI countries (50%) but is much less than MI (100%) and HI countries (80%) [51]. The low referral rate for this type of assessment can be traced back to the lack of HCPs' knowledge of PNES and possible treatment options, as well as insufficient access to psychologists who can treat patients with PNES [50]. Healthcare professionals rarely referred PWE for such assessments, notwithstanding growing evidence that the psychological and social domains have the greatest impact on the quality of life in PWE, the most important treatment goal for ES remains freedom from seizures [58]. This reflects the perception that MES should primarily be treated with biological interventions, which results in a disregard for the psychosocial aspects of ES and an exclusive focus on the physical symptoms of the seizures [59].

#### 4.4. Communication of the diagnosis

It is of utmost importance to carry out the delivery of the PNES diagnosis to the patient in a sensitive and considerate manner and to make it clear that the physician believes the attacks to be genuine and not volitionally produced [60–62]. Some studies show that seizure frequency can be reduced by simply providing patients with a diagnosis

of PNES [63,64]. In the case of ES, which is a heavily stigmatized condition, it is imperative that the HCP refrains from using pejorative terms when communicating with the patient [20,57]. It was therefore heartening that HCPs in the present study acknowledged the significance of the way in which the diagnosis is imparted and what phrases and terminology are best suited to explain the causes and possible treatment to the patient. The explanations showed that HCPs endeavor to minimize the effect of stigma, to assure the patient that the seizures are not deliberate but that it should be taken seriously, and to regularly include the family in discussions [50]. However, Namibian respondents less frequently involved the family when imparting a diagnosis of ES/PNES. Compared with responses from Chile, the US, and the UK that stated values of more than 90% [52–54], Namibian HCPs reported that the family is involved less than 60% of the time. In addition, few of the HCPs indicated that they supply patients with additional sources of information or inform other HCPs in the referral chain of the diagnosis. This may contribute to a lack of coordination and feedback between treating practitioners with resultant delays in effective management [50].

#### 4.5. Follow-up, treatment, and referral

A noteworthy difference between the ES survey and the PNES survey was the rate of follow-up of patients. The HCPs in the ES survey follow up significantly more often than the practitioners in the PNES survey. The reasons for follow-up given by HCPs in the ES survey center on biological management such as the supervision of AEDs and other medications that were prescribed, whereas patients with PNES are offered at least one follow-up visit after the diagnosis had been communicated to them, albeit in less than 50% of cases. Lack of regular follow-up by HCPs ties in with referral practices among service providers which were explored in a previous study [50]. This study found that HCPs see themselves as playing a specific role in the diagnosis and treatment of PNES, but they seldom communicate with other professionals who may be involved with the patient at the same time. This failure of cross-disciplinary collaboration results in a lack of patient ownership and feelings of abandonment and uncertainty in patients [65].

Indecision regarding the most suitable treatment method for PNES often results in the perception that it is a difficult disorder to treat [66,67]. However, several studies found that a cognitive behavioral therapy (CBT) approach to psychotherapy yields more positive results in the treatment of PNES compared with other psychotherapeutic approaches [22,68,69]. Responses from the PNES survey considered individual psychotherapy as the treatment of choice for PNES followed by antidepressants. Namibia's referral rate to psychologists/psychiatrist for the treatment of PNES compares poorly with other countries. Survey responses estimated the proportion of patients who will be offered at least one appointment for psychological/psychiatric treatment as 55% compared with those in Chile (84%), the US (72%), and Brazil (84%) [52–54]. The Namibia referral rate is more in line with LI countries (50%) compared with MI (35%) and HI (80%) countries. In the ES survey, HCPs indicated AEDs as the preferred method of treatment followed by individual psychological treatment, which is surprising given the low referral rate to such practitioners.

In the PNES survey, HCPs indicated the lack of collaboration between HCPs and THPs as one of the challenges in providing adequate healthcare. It was, therefore, deemed essential to explore this response in more detail in the ES survey. The role of TM in the African region is becoming increasingly apparent, with 39 out of 46 countries in Africa introducing National TM offices, while 24 have implemented TM programs in their ministries of health [70]. In Africa, TM is used to meet the healthcare needs of approximately 80% of the population [43]. Accessibility plays a major role in the widespread use of THPs in Africa where there is a lack of skilled medical doctors in general and where healthcare services are often located in urban areas [11,71]. The ES survey responses made it clear that HCPs recognize that some patients

prefer to be treated by THPs and that these practitioners may play a supportive role in the management of seizures. Despite HCPs' willingness to collaborate with THPs, they did, however, indicate their reluctance to refer patients to THPs as the role of THPs is seen mainly as supportive and not critical to the diagnostic and treatment process of seizures.

#### 4.6. Etiological factors

According to the literature, PNES may develop as a result of complex interactions between psychosocial and environmental factors [72–74]. In the PNES survey, HCPs identified a broad range of possible etiological factors for PNES, such as family conflict, accumulated life stress, depression and anxiety, potential sexual abuse, and comorbid personality problems. It is interesting that there were marked differences between etiological factors in this study compared with previous research evidence. Whereas trauma featured strongly in ES survey responses and in studies conducted in the US and other HI countries, this was not the case insofar as PNES in Namibia are concerned [51,52]. Family conflict and anxiety were more commonly stated as causes for PNES which corresponds to reports from Chilean and Brazilian respondents where anxiety was thought to be most prevalent [52,54]. These responses support the Integrative Cognitive Model of MUS, which explains the manifestation of PNES as the result of predisposing, precipitating, and perpetuating factors [75]. It also highlights the influence of cultural and societal perceptions on the possible causes of seizures.

Responses from the ES survey reported the etiological factors most prevalent for ES in Namibia as head trauma, progressive brain disease, other medical problems, and alcohol abuse. A high incidence of motor vehicle accidents and parasitic infections in developing countries can explain why head trauma and progressive brain disease rank as the most common causes of epilepsy in Namibia [57].

#### 4.7. Barriers to healthcare

Consistent with evidence from the worldwide study on PNES, Namibian respondents most commonly stated financial limitations and lack of information as the main obstacles when it comes to the diagnosis and treatment of seizures [51]. Surprisingly, stigma was mentioned as the least significant barrier by our respondents whereas this was more commonly mentioned around the world [51]. Participants in both surveys listed financial constraints as the most significant obstacle in accessing healthcare services. Seizure disorders are expensive conditions to have because of the costs involved in consulting various specialists and having to undergo multiple tests and investigations to arrive at a diagnosis. The same concern is evident from the literature, which states that to diagnose PNES in a person, considerable costs are incurred over an extended period for numerous procedures, tests, and treatments [35]. These concerns are followed by lack of popular awareness and lack of information regarding PNES and ES, which applies to both the public and HCPs. These particular barriers are less dependent on financial factors and may be successfully addressed through campaigns aimed at increasing awareness about seizures and training opportunities for HCPs [56,76].

#### 5. Limitations

Similar to a previous study conducted by du Toit and Pretorius [50], the sample consisted of HCPs currently in private practice and did not include professionals in full-time government employ. However, some of the specialists and GPs either consult for the government or had been employed by the government in the past. A further limitation is that HCPs were recruited from the three most central towns in Namibia and may therefore not represent providers across the whole country.

Second, both samples were dominated by GPs. This may be ascribed to the lack of specialists in Namibia and the reliance on GPs to serve the

bulk of the population. It is regrettably a true reflection of the current situation in Namibia [50].

Third, the response rates of 28.74 and 35.21% in the samples may be deemed consistent with previous uncompensated surveys that focused on responses from health service providers, which stated a response rate of between 8 and 45% [54].

Finally, the proportions reported in the survey are based on HCPs' recollection of patients whose disease was diagnosed, managed, and investigated rather than on actual data. None of the HCPs in this study kept records of actual data or patient encounters and, therefore, relied solely on memory and overall impression. Moreover, in view of the differences in medical care practices, socioeconomic conditions, cultural perceptions, and the financial framework in which HCPs practice in Namibia, the findings of this survey cannot necessarily be generalized to other countries.

#### 6. Conclusion

Despite the methodological limitations, this study was a first for Namibia and paved the way for future research on seizures in developing countries. Although limited access to specialized services and lack of financial resources featured strongly among the responses from HCPs, lack of knowledge and awareness about seizure disorders play a major role in how these conditions are managed. Insufficient economic resources limit the provision of services and are difficult to address; however, campaigns aimed at increasing HCP education may contribute significantly to alleviating the seizure burden. In an effort to understand the role of THPs in the management of seizures, we are currently conducting a study to explore the experiences and roles of traditional and faith healers and how seizures are customarily perceived and treated in nonwestern cultures. A study of this nature may address the knowledge gap between traditional and conventional healthcare providers in an attempt to improve quality of care for patients with seizures in Namibia. Secondly, the proposed multilayered investigation could form the basis for future investigations into government policies regarding the provision of adequate healthcare facilities and regulatory bodies that recognize the role of THPs in healthcare provision.

#### Declaration of interest

None of the authors declare a conflict of interest.

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### Chapter 6: Manuscript 3

**Title:** Epilepsy: Namibian healthcare providers' perceptions and experiences

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**Brief Summary:** In this full research article, we report the findings from semi-structured interviews conducted with HCPs. This qualitative study focused on exploring the perceptions and frustrations of HCPs in the diagnosis and treatment of ES in Namibia. Thematic analysis was used to identify the four main themes and related subthemes. It was evident from the analysis of the interviews that the perceptions and frustrations of HCPs centred on the areas of diagnosis, treatment, patients and awareness. The four systems of the ecological systems theory (Bronfenbrenner, 1977; 1979) were used to conceptualize the discussion of the subthemes and findings were linked to the existing literature on ES. We also discuss the implications of the findings, limitations and suggestions for future research.

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## **Epilepsy: Namibian healthcare providers' perceptions and experiences**

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### **ABSTRACT**

**Purpose:** Epilepsy is the most common, chronic and severe neurological disorder in sub-Saharan Africa (SSA) and involves a major burden of costs, mortality, stigma, seizure-related disability and comorbidities. However, most studies conducted on the diagnosis and treatment of epileptic seizures (ES) have been performed in developed countries, with developing countries, receiving less attention. This study aimed to contribute to the goals of the International League against Epilepsy (ILAE) by investigating the perceptions and experiences of Namibian healthcare providers (HCPs) in managing ES.

**Methods:** Fifteen HCPs from the private healthcare sector in Namibia were recruited to participate in semi-structured interviews. The semi-structured interviews were analysed using thematic analysis to identify themes and subthemes in the data. These themes were subsequently interpreted from the perspective of the different levels of Bronfenbrenner's Ecological Systems Theory.

**Results:** The main themes identified in this study centred on the diagnosis, treatment, patients and knowledge about ES. It was evident from the findings that Namibian HCPs encounter several challenges in the management of people with epilepsy (PWE). The barriers that a developing country such as Namibia faces were evident in subthemes that highlighted the widespread use of traditional health practitioners (THPs) in the treatment of epilepsy, the lack of access to specialised equipment and services and under-resourced state health facilities.

**Conclusion:** The compound effect of the population's low socio-economic status and lack of knowledge about ES paints a bleak picture of the current situation of epilepsy in Namibia.

**Keywords:** Namibia; sub-Saharan Africa; Epilepsy; Healthcare providers; Traditional healers; Qualitative;

## 1. Introduction

One cannot overstate the importance of examining the possibilities for diagnosis and treatment open to PWE in SSA, especially since epilepsy touches the lives of between 65 and 70 million people across the world, with, between 80 and 90 per cent found in developing countries [1,2]. Epilepsy is, therefore, the most common, chronic and severe neurological disorder in SSA. The disorder brings with it a major burden of costs, mortality, stigma, seizure-related disability and comorbidities [3,4]. However, no official statistics or diagnostic and treatment guidelines on epilepsy are currently available in Namibia (H. Riphagen, Personal communication, Epilepsy Namibia, 27 June 2016).

Countries that fall into the World Bank's classification of Low and Lower Middle Income (LMIC) based on gross national income per capita, are often poorly equipped to deal with the immense economic, medical and social burden that epilepsy brings [5]. Most of these resource-poor countries are located in SSA, parts of Asia, Latin America and the Pacific regions. They often battle with challenges such as inefficient healthcare systems, widespread poverty and unevenly distributed material resources [5]. On top of that, "The few efficient health care facilities that exist in these countries predominantly benefit people who reside in urban areas and those belonging to the economically advantaged section of society, and rarely benefit the poorer sections of the population who live mostly in rural areas" [5]. Namibia is no exception. Secondary and tertiary healthcare is more accessible to the affluent urban population of Namibia than to the rural poor [6].

Namibia is a country in Southwestern Africa, bordering on South Africa with a surface area of 824 116 km<sup>2</sup>. It gained independence in 1990 after being a mandate of South Africa from 1922 to 1966 and a German protectorate before that.

The World Health Organization estimated the Namibian population at 2 459 000 in 2015, with a population density of 2.2 persons per square kilometre [7]. This relatively low population and density is marked by cultural diversity with nine defined ethnic groups and

thirteen national languages [8]. English serves as the official language of Namibia, despite being a minority language [8].

The country is divided into 14 administrative regions, with the Khomas Region being the most central. The capital, Windhoek, is located in this region, accommodating the two largest hospitals in the country both state-owned and operated.

Even though the World Bank [9] classifies Namibia as an Upper Middle Income country, it is ranked 128 out of 168 countries in terms of its Human Development Index [10]. As an added indication of the situation in Namibia, a GINI Index of 0.597 ranks Namibia as one of the most unequal countries in the world when it comes to the distribution of income [10]. This is starkly clear from the estimated poverty incidence of 29 per cent with a further 15 per cent of the Namibian population living in severe poverty. The HIV/AIDS prevalence is 18.2 per cent and the unemployment rate is 27.4 per cent [10]. In 2012, neurological disease/disorders were rated as one of the top ten causes of death in outpatients [10]. Tuberculosis (TB) and Malaria remains prominent causes of death in Namibia. The general government expenditure on health as a percentage of total health expenditure is 60.4 per cent. Only 18.65 per cent of the total health expenditure is covered by private health insurance, the remainder is out-of-pocket [7].

Epilepsy entails more than just seizures. The condition often has many everyday implications for independent living, social and employment situations and academic advancement [11]. In developing countries where patients have less access to healthcare infrastructure and manpower, the successful management of epilepsy is crucial.

The aim of this study was to identify the perceptions and experiences of Namibian HCPs regarding the diagnosis and treatment of PWE and to lay the foundation for future studies to focus on improving the quality of care for seizure patients in Namibia.

## **2. Methods**

### *2.1 Participants*

ES are commonly diagnosed at epilepsy monitoring units with the use of EEG and medical examination by a neurologist [12]. Namibia does not have an epilepsy-monitoring unit.

The country is served by only three neurologists, two situated in Windhoek and the other in Oshakati in the far north of the country. According to the WHO, Namibia has 0.374 physicians per 1000 people, 12 psychiatric beds per 100 000 people, 4.78 computerized tomography (CT) units, 0.87 magnetic resonance imaging (MRI) units and 0.77 electroencephalography (EEG) monitors per million people [7]. No video-EEG (vEEG) monitors are available. Due to the lack of specialists, the majority of the population rely on general practitioners (GPs) and other primary healthcare workers for their healthcare needs.

Purposeful sampling was used to identify participants from the available healthcare service providers' pool in Namibia. Recruitment occurred between May 2017 and August 2017. The Health Research Ethics Committee at Stellenbosch University granted ethical approval for this study (protocol number: REC-050411-032). Eligibility for participation in the study was based on the speciality of the healthcare provider. HCPs were sourced from the private healthcare sector since few specialists are employed by the public sector. Involving the neurologists in the study was vital considering the limited availability of specialists. GPs were identified based on experience in treating epilepsy, years in practice and special interest in neurology and psychology.

## *2.2 Data Collection*

The Namibian telephone directory lists approximately 180 GP entries, of which the majority includes e-mail addresses. This directory was used to identify participants as listings for GPs indicated specific specialization areas such as family practitioner, obstetrics and psychiatry. Obtaining information on neurologists proved much simpler given their limited numbers. A list of possible service providers was compiled, giving preference to neurologists and GPs with specializations. Preference was also given to GPs who were accessible in and around Windhoek due to logistical and time constraints.

Twenty HCPs were invited to participate in the study. This included two neurologists, one gynaecologist and 17 GPs. The present study forms part of a larger study that investigated the perceptions and experiences of HCPs regarding the management of seizures. A Continuous

Professional Development event for HCPs held in Windhoek offered an opportunity to invite HCPs to participate in the epilepsy part of the study. During this event, seven HCPs indicated their willingness to be interviewed. These candidates were contacted telephonically to arrange a meeting at a time and place that suited them. In five cases, documentation packs were hand-delivered to their offices before the interview. The documentation consisted of: (1) letter of invitation, (2) informed consent form, (3) biographical questionnaire, and (4) semi-structured interview questions. In two cases, the HCPs practised in towns near Windhoek, and the information was e-mailed to these participants. The remaining 13 HCPs were first contacted telephonically to enquire whether they would consider participating in the study. In cases where the answer was favourable, the procedure described above was followed. All HCPs were contacted by telephone to ensure that the relevant documentation was received in good order and to confirm the appointment. All the HCPs were interviewed at their consulting rooms.

Semi-structured interviews were conducted with 15 participants. Before conducting the interview, the relevance and purpose of the study were explained and questions regarding the research were answered. The HCP was asked to read and sign the informed consent form and to complete the biographical questionnaire that explored the HCPs' qualification, speciality (if any), years in practice and location. Permission was requested from the HCP to record the interview for transcription purposes. The interview consisted of broad, open-ended questions based on the epilepsy survey for HCPs that was developed to explore the diagnostic and treatment practices of HCPs. This questionnaire was used in the quantitative part of the larger study. The semi-structured interviews aimed to gather detailed information and personal opinion regarding the diagnosis and treatment practices used for seizures and specifically epilepsy in Namibia (see Table 6.1).

Table 6.1. *Questions that were used to guide interviews.*

Number	Questions
1	Tell me about your work with seizure patients.
2	What are the complexities involved in making a diagnosis of epilepsy?
3	How easy is it to access tests such as EEG, vEEG and specialists?
4	How is the diagnosis communicated to the patient?
5	What are your thoughts on the role of stigma in epilepsy?

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|----|---|
| 6  | What are the general attitudes/reactions when people are diagnosed with epilepsy?                       |
| 7  | What are in your experience the main causes of epilepsy in Namibia?                                     |
| 8  | What role does secondary gain play in the diagnosis?  |
| 9  | What is your opinion regarding referral of PWE to a mental health professional?                         |
| 10 | What would you consider the most effective treatment for epilepsy? The availability of this in Namibia? |
| 11 | What do you think about the role of traditional healers in the management of seizures?                  |

Participants were prompted to elaborate on their perceptions and experiences during the interview to obtain as much information as possible. Interviews lasted up to 60 minutes. Each interview ended by thanking the HCP for their time and willingness to participate. Participants were informed that a transcript of the interview would be e-mailed to them so that they can verify the information.

### 2.3 Data Analysis

The same data analysis procedures were used as described in a study by du Toit and Pretorius [13]. Thematic analysis was used to analyse the qualitative data from the semi-structured interviews [14]. The data analysis was guided by Bronfenbrenner's Ecological Systems Theory (EST) [15], combined with a mixed inductive approach. The EST was used to describe the perceptions and experiences of HCPs in a holistic manner by interpreting the ideas and understanding they have of epilepsy, themselves and their environments.

A transcription service transcribed the individual interviews to ensure crosschecking of content and professionalism. The transcriptions were compared to the original recordings to ensure that it is an accurate representation of the original interview. This also allowed the researchers to become more familiar with the scope of the data. Noting interesting features in the data during a rereading of the transcripts formed the basis for the next five phases of analysis (see Table 6.2).

Table 6.2. *Stages of thematic analysis [see, 13].*

Stages	Action(s)
1	AdT listened to audio recordings and compared it to transcriptions of the interviews. To become more familiar with the content, interviews were reread repeatedly.
2	Initial codes were generated using hard copies of the interview transcripts. Microsoft OneNote was used to electronically group marked portions of the data under different pages in one section. It was a timeous process to combine some pages and eliminate others in order to form a coherent picture of the data.

- 3 Thematic networks were used as an illustrative mind mapping tool in order to organize themes according to the various systems of the EST (Attride-Sterling, 2001).
  - 4 Reviewing and refining of themes by rereading collected extracts and comparing it to the entire data set to determine whether the final thematic network accurately represented the data. CP then reviewed the themes and coding structure to ensure that it was a true reflection of the data set.
  - 5 Refine and define the themes previously identified. Organized themes into a coherent whole and wrote a detailed analysis of each theme.
  - 6 Writing the report, relating the story of the data in a logical, continuous and interesting way with enough evidence in the form of direct quotes to support the themes.
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#### 2.4 Maintaining trustworthiness

To ensure trustworthiness, the same measures that were applied in a study conducted by the Toit and Pretorius [13] were used in this study: “Credibility, transferability, dependability and confirmability were used to ensure trustworthiness in this study [17] (see Table 6.3). Peer debriefing, peer examination and member checks were used to ensure that the data were represented fairly and truthfully [18,19]. Reflexivity and triangulation were used to ensure that the study truly reflected the informants’ perceptions and excluded the beliefs and biases of the researchers [20,21].”

Table 6.3. *Process of maintaining trustworthiness [see, 13].*

Process	Sub-process	Description of steps taken
Credibility	Peer debriefing	Regular discussions between authors at various stages of the project to explore emerging ideas and areas of concern regarding the study.
	Peer Examination	The research proposal for the study was screened by the Departmental Ethics Screening Committee and Research Ethics Committee: Human Research (Humanities) at Stellenbosch University before the study.
	Member Checks	Participants had the opportunity to confirm the content of interviews, both during the interviews and after data transcription.
Transferability		Detailed contextual information was provided about the research context, processes and participants to enable users to draw their own conclusions regarding the transferability of the findings.
Dependability		Detailed descriptions of the context, research methodology, implementation and findings are provided to enable future researchers to repeat the study.
Confirmability	Reflexivity	In order to minimize the impact of researcher bias, a descriptive profile for each HCP was diarized to reflect on the interviewing process by noting own impressions and some of the reactions observed in HCPs.
	Triangulation	Multiple data sources were used from different sectors of the healthcare system. Method triangulation was used as this study is a subset of a larger study that used quantitative data in the form of questionnaires to illuminate the qualitative data. Theoretical and researcher triangulation were achieved through

the collaboration of the authors who compared findings from different disciplines and positions.

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### 3. Results

Semi-structured interviews were conducted with 15 participants. This included two neurologists, one gynaecologist and 12 GPs. The number of interviews depended on theoretical saturation and by the fifteenth interview, various themes had been mentioned repeatedly and no new information was emerging [22].

Years in practice ranged from eight to 47 years (median = 20) and the average age from 34 to 74 years (mean = 48.5). Twelve of the participants were male and three were female. The participants consisted of six Black, two Mixed and seven White individuals (see Table 6.4).

Two of the GPs indicated specialization in psychiatry and psychology, while the other GPs specialized in occupational health, aviation and travel medicine and HIV medicine. Five of the HCPs practice in Rehoboth, 90 kilometres south of Windhoek. The population consists of small-scale farmers, artisans and people who commute to Windhoek daily for reasons of employment. The preferred language is Afrikaans, and most of the people are of mixed origin. Two of the participants practise in Okahandja, 70 km north of Windhoek. The population is more urban than Rehoboth, with many residents commuting to Windhoek daily. It is a gateway to the North and West of the country and houses smaller scale industries, factories and a military base.

Table 6.4. *Demographic information of participants.*

P	Age	Gender	Race	Qualification	Years in Practice
1	53	F	White	General Practitioner	25
2	61	M	White	General Practitioner	31
3	60	M	White	General Practitioner	35
4	43	M	Black	General Practitioner	18
5	50	M	Mixed	General Practitioner	13
6	39	M	Black	General Practitioner	14
7	42	M	Black	General Practitioner	13
8	46	M	Mixed	General Practitioner	20
9	49	F	White	General Practitioner	23
10	53	M	White	General Practitioner	30
11	74	M	White	Gynaecologist	47
12	36	M	Black	Neurologist	13
13	34	M	White	General Practitioner	8
14	47	F	Black	General Practitioner	20
15	41	M	Black	Neurologist	17
Mean 48.5		M: 80%	6B;2M;7W		Median 20

P = Participant, F = Female, M = Male

Four main themes emerged as the most common areas in which HCPs expressed perceptions or experiences regarding epilepsy. These themes centred on diagnosis, treatment, patients and knowledge. Results are reported according to the main themes and are categorized into the micro-, meso-, exo- and macrosystems of the Ecological Systems Theory [15]. Thereafter, subthemes are described as either perceptions or experiences to provide a more complete understanding of the information. Results from the thematic analysis are illustrated in Table 6.5 and Figure 6.1.

Table 6.5. *Emergent main themes and illustrative quotes.*

Main Theme	Illustrative quote
Diagnosis	<p>“We make a preliminary diagnosis here in the consulting room and then you try to confirm it with a referral for an EEG or to a neurologist. We take a history and we get collateral information, but it is not always easy.” (Q1)</p> <p>“The parents need time for it to sink in, the first time you tell them they don’t really grasp what’s going on. Most of the time I send them to the specialist, and when they come back they’ve got a better appreciation and they tend to ask more questions and want to understand.” (Q2)</p> <p>“I normally send all of them for EEGs and a CT scan to exclude brain pathology. Even if both of these are clean, you can’t say that they don’t have epilepsy. But if they have another seizure, then you have to treat it. It is often a clinical diagnosis, but it must be confirmed with special investigations.” (Q3)</p> <p>“Resource limitations are a huge challenge in our part of the world. Patients don’t have money to attend the healthcare professionals, it’s costly, and the fact that they don’t work also limits them from accessing healthcare and the cost of drugs becomes prohibitive. That stuff is expensive!” (Q4)</p> <p>“In the rural areas it is very difficult to make a diagnosis because you can’t always send a patient to Windhoek for an EEG, especially if it is a state patient. It is too far. Sometimes</p>

- you send them, and then they are told the EEG machine is broken and they must come back later.” (Q5)
- “The problem with the state is efficiency, that's how the people end up coming here because you go there, the first thing is the queue itself, people don't want to wait so long. We are sitting with a hospital that has vacancies, the nurse complement there is just too low. To update it according to the size of the hospital is taking forever. So things in this state, they just take long.” (Q6)
- Treatment “Normally the first thing is to control the seizures. Depending on how well we are controlling the seizures, then obviously you want to do an EEG.” (Q7)
- “The medication is reasonably available. Cost is of course also a factor, but the normal stuff like Tegretol and Epilim is available.” (Q8)
- “I do regular follow-ups because some of this medication can be toxic to the liver and we are also legally responsible to follow up people on AEDs.” (Q9)
- “As health practitioners, we diagnose epilepsy and then we prescribe medication. That's all. Maybe we need to send the patient to psychotherapy. We don't really consider that.” (Q10)
- “There are lots of side effects. For example, one patient's hair fell out. The other one got eczema. It influences their concentration and it doesn't go well with alcohol.” (Q11)
- “When various drugs don't work and we've pushed it to its maximum dose we have to consider epilepsy surgery. We unfortunately don't have that service here. So we normally send our patients to Cape Town.” (Q12)
- “They get angry if a private doctor sends a patient to the state. Whether it is psychologists, social workers or doctors that work there they hate the private sector. And then they let them wait and send them from the one doctor to the other.” (Q13)
- “I might mention a traditional healer, plant a seed. But I won't say go, I will let them decide for themselves. I think it can help but then it must not be on their own. It must be teamwork and then you might get a better result. Look, they are important in the community and I think in our community there are more healers than normal doctors. I would like to hear what they say and decide for myself if I want to use this guy or not because I think just like in the medical profession, there are many fly-by-nights.” (Q14)
- Patients “I've seen burns, bruises when they fall down. I had to admit patients for burns that were sustained when they were having fits, the one was on the hand, and the other one was in the face.” (Q15)
- “You do get patients who are saying that they are now literally waiting for the next seizure. So they are frozen in terms of their activities, they are afraid to go out, they are afraid to go to school, and there are changes of behaviour in terms of being defensive, and even anger.” (Q16)
- “People stop drinking their medication because they get tired. It's like fatigue, especially if it's not so frequent, if they take the medication and they don't get many seizures there is false security that now the disease is gone and they suddenly stop the medication.” (Q17)
- “One of the difficulties of our community is you cannot really say this is my patient. They will come here, then they shop there, then they shop there, epileptic patients are not loyal because they are trying to find answers. If I tell them that this is something which is chemical, there is no solution except to take medication. I am not telling them what they want to hear, and then they obviously go to another one and seek another opinion until they get to a point where they have accepted.” (Q18)
- “Then you find the ones that feel that they are being discriminated against and then they start using it for secondary gain. They think well, I don't have to do anything, I am sick, I must get a disability grant.” (Q19)
- “There is still a high proportion of patients that think they are bewitched, which is a big challenge even after diagnosis. They still consult the traditional healer for a second opinion to identify any underlying sort of bewitchment.” (Q20)
- “Patients cope better when there is good family support and structure” (Q21)
- “If they continue to have seizures you look at other things like, did they drink a lot, sit in the sun, are they hypoglycemic, and with young people that watch a lot of music videos, they get it a lot.” (Q22)

- Knowledge “If you are a bus driver or a public transport driver you cannot drive the bus for 10 years. A pilot cannot be a pilot even after one seizure. So epilepsy does change people's lives. You can't be a plumber who has to go down the drains or an electrician so we encourage our patients to be better educated than the rest to improve their future quality of life. You have to tell them that they might be better off choosing an office job, as compared to an outdoor job. So as a disease epilepsy is limiting to a certain extent.” (Q23)
- “Some GPs will send patients with chronic epilepsy to the physicians knowing that there are neurologists around. Physicians, they do have an idea but they are not neurologists. Sometimes the GP would change medication without consulting which is a bit frustrating. A lot of the GPs give me a call especially in the rural areas because state patients can't just come to Windhoek, but still, some don't. So that's probably a challenge that we need to address.” (Q24)
- “We have a lot of infectious epilepsy from the North with neurocysticercosis, parasitic infections. We have no epidemiological data, and ideally this is what we need to get. We don't know the nature of the beast because we just don't have the data in terms of prevalence or incidence of epilepsy.” (Q25)
- “Most of us practitioners are actually not very comfortable dealing with epilepsy and neurological conditions. It is a difficult area and we don't really get good exposure. During training there was no neurological rotation, it is part of the general medical rotation. Postgraduate, post internship, the training is also very minimal. You need a high degree of motivation to deal with neurological conditions, so we need to push, as much as we can to inform the community and the health workers need to be educated more in that.” (Q26)
- “It is necessary to educate the community that if a person with epilepsy collapse in a supermarket we don't just crowd around or run away. We must help them. It is a medical emergency. We must treat it just like anyone who has fallen and they are bleeding. We must empower them to understand what the disease is about, to remove the stigma, to encourage positive health seeking behaviour for people to go to the hospital see a doctor.” (Q27)
- “They still consult the traditional healer for a second opinion which is a huge barrier to care because it often delays presentation. The patient just doesn't come early enough.” (Q28)
- “There's a big stigma. They just don't want to be around such people, nobody wants to employ them, because when they have their seizures, they don't know what to do.” (Q29)
- “Our people are poor, it's someone who is on the government medical aid and that co-payment, that extra N\$50, prevents them from taking the medication. But then they go to the state and then the medication changes and they start fitting again because the state don't have the whole range that you have in private practice. I think that that should qualify them to get social grants.” (Q30)
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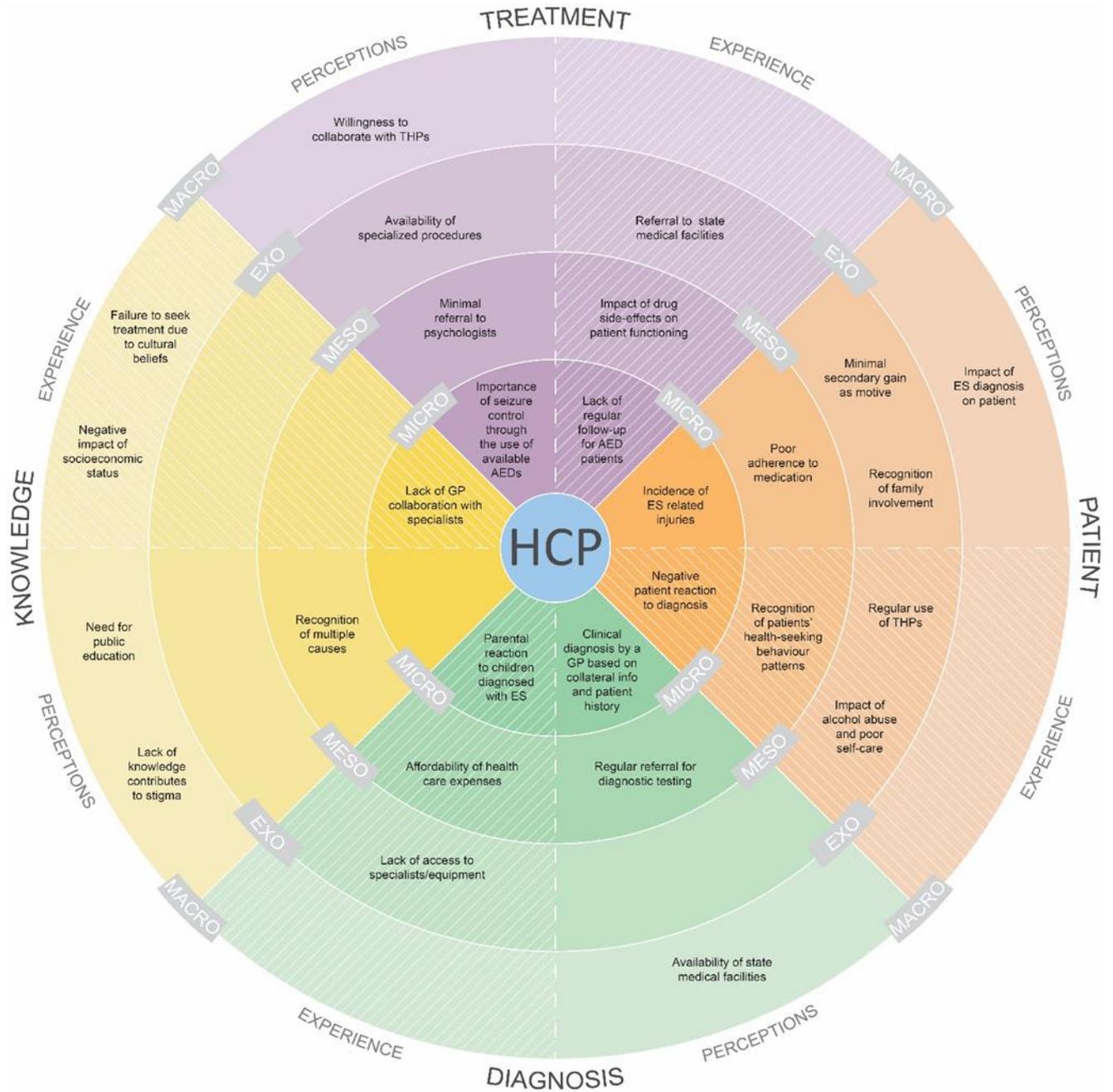


Figure 6.1. A graphical illustration of the main themes and subthemes according to the different levels of the Ecological Systems Theory.

### 3.1 Theme 1: Diagnosis

#### 3.1.1 Microsystem

***A clinical diagnosis by a GP based on collateral information and patient history.*** All the GPs indicated that the preliminary diagnosis of epilepsy is a clinical one based on an extensive medical history of the patient and a description of how the seizure manifests (Q1). Eight HCPs mentioned the importance of gathering collateral information because “the patient normally doesn’t know what is going on”. However, only one GP and one neurologist mentioned that smartphone images of the event may be valuable during the diagnostic process. In addition, one of the neurologists admitted that PWE are usually managed by GPs and that it is only “the complex cases that make it to the neurologist”.

***Parental reaction to children diagnosed with ES.*** Six of the HCPs described that parents often experience feelings of “personal failure”, “denial” and “shock” when their child is diagnosed with ES. One GP described it as “very difficult for parents to accept and they seldom want to discuss it” (Q2).

#### 3.1.2 Mesosystem

***Regular referral for diagnostic testing.*** Eleven of the GPs stated that they regularly refer patients for a CT scan and EEG monitoring to confirm the diagnosis (Q3). However, two of the GPs recognised that if the EEG “is negative you can’t say that he does not have epilepsy”. Some of the GPs indicated that they wait for the patient to have a second seizure before they refer for diagnostic testing.

***Affordability of healthcare expenses.*** Referral to specialists for confirmation of the diagnosis is often hampered by lack of financial resources as described by five of the HCPs (Q4). It was stated that some patients simply cannot afford to go to a neurologist and “If they cannot afford it, I send them to a physician to only get a scan”.

### 3.1.3 Exosystem

**Lack of access to specialists/equipment.** Ten HCPs mentioned travel distances from the rural areas to see specialists and undergo testing in Windhoek as one of the key frustrations (Q5). In addition, the three EEG monitors in the country are owned by private practitioners and GPs in the rural areas are often forced to “eventually just give the patient what you think is necessary”.

### 3.1.4 Macrosystem

**Availability of state medical services.** HCPs are often compelled to use state health facilities for patients who cannot afford private services. However, nine HCPs described budgetary constraints, lack of nurses and doctors, long waiting periods and shortage of suitable medication in the state as a “nightmare” (Q6).

## 3.2 Theme 2: Treatment

### 3.2.1 Microsystem

**Importance of seizure control with available AEDs.** All the HCPs agreed that when a patient presents with an ES, the main aim is to prevent subsequent seizures with AEDs (Q7). Most of the HCPs indicated that AEDs are reasonably available in Namibia, with Epilim and Tegretol being the most preferred drug treatment (Q8). However, there were differences about when AED treatment is started, with some GPs indicating that AED treatment commences immediately after the first seizure, while others first refer for diagnostic testing or wait until the person has a second seizure before introducing AED treatment.

**Lack of regular follow-up for AED patients.** Only four HCPs mentioned that they regularly follow up on patients on AED treatment (Q9). HCPs ascribed the need for regular follow-ups to “blood tests every six months to check the liver function”.

### 3.2.2 Mesosystem

**Minimal referral to psychologists.** Even though eleven of the HCPs acknowledged that patients might benefit from psychological services when diagnosed with ES, none of the HCPs in the study refer PWE to a psychologist as part of their management plan (Q10). However,

HCPs stated that they would consider referring if they notice signs of “stress, anxiety or depression”.

***Impact of drug side effects on patient functioning.*** Nine of the HCPs stated that AEDs often cause adverse effects such as “unwanted weight gain”, “tiredness, drowsiness, dizziness” and “neurocognitive side-effects” (Q11). Older drugs like phenytoin are associated with “Hirsutism, they grow hair and become ugly” whereas Epilim “has issues with metabolic disturbance, causes liver impairment and movement disorders”.

### 3.2.3 *Exosystem*

***Availability of specialised procedures.*** Eight of the HCPs stated that they are aware of epilepsy surgery and vagal nerve stimulation as alternative treatment methods for patients with refractory epilepsy (Q12). However, these procedures are only performed at Constantiaberg in South Africa and only five of the HCPs indicated that they have referred patients for this in the past because it is “very expensive” and that “I have not seen one of them where the epilepsy is completely gone”.

***Referral to state medical services.*** Ten of the HCPs expressed frustration when asked about referral procedures to state medical services (Q13). The HCPs indicated that “there is a lot of antagonism from the state towards the private sector” and that “if we send the patient to the state, they just ignore them, they hate it, they just tear up your referral letter”.

### 3.2.4 *Macrosystem*

***Willingness to collaborate with THPs.*** Most of the HCPs had an overwhelmingly positive response when asked about their perceptions regarding the role of THPs in the provision of healthcare (Q14). Eight of the HCPs indicated that they would be prepared to “speak to a healer just for interest sake” and four HCPs stated that they “have advised the patient before to see a THP because sometimes there is a missing cultural link”. Three of the HCPs raised concerns about “lack of regulation of THPs”, “mistrust and blaming” although they also

mentioned that “they augment the healthcare profession very much” and “they work with the psychological aspect of the patient”.

### 3.3 Theme 3: Patients

#### 3.3.1 Microsystem

***Incidence of ES -related injuries.*** Six of the HCPs stated that they have treated PWE for injuries sustained as a result of ES (Q15). The most obvious injuries included “burns”, “bruises and tongue that was bitten”, “car accidents or dislocated shoulders”, “abrasions” and “big lacerations”.

***Negative patient reaction to diagnosis.*** HCPs indicated that patients “sort of expected” the ES diagnosis although only “50 per cent understand it completely”. Ten HCPs mentioned feelings such as “anger”, “fear and denial”, “blaming”, “really shocked” and “a terrible thing” to describe patients’ reaction to receiving a diagnosis of ES (Q16).

#### 3.3.2 Mesosystem

***Poor adherence to medication.*** Eleven of the HCPs stated that although some patients adhere to the medication, a larger proportion “only drink medication in the beginning” (Q17). In HCPs’ experience, PWE often discontinue treatment “when they feel better” or “adjust their medication themselves”.

***Recognition of patients’ health-seeking behaviour patterns.*** Eight of the HCPs stated that patients often “do the loop between the neurologist, the medical practitioner and the healer” (Q18). This behaviour was most often ascribed to patients’ need for “a second opinion” and because “they want zero seizures”.

#### 3.3.3 Exosystem

***Minimal secondary gain as motive.*** HCPs seldom mentioned secondary gain as a motive in ES (Q19). Only three of the HCPs indicated that PWE might express the desire to be “boarded” or “to get the state disability grant”.

**Regular use of THPs.** An overwhelming majority of the HCPs acknowledged that they are aware of patients going to THPs for treatment (Q20). They stated that the patients “believe in them and what they tell them”, “they have the diagnosis blessed and then they continue with the treatment”, “they bring some assurance to the patient” and “if they are looking for a permanent cure they will go and ask at the traditional healers”.

**Recognition of family involvement.** Five of the HCPs stressed involving the family in both the diagnostic and treatment process by saying that “if they have a good support structure at home, then they are normally fine” (Q21). HCPs also indicated that the family have to be informed of the diagnosis because “it makes it more acceptable for the patient” and “they must all understand what is going on and the potential dangers and the follow-ups”.

**Impact of alcohol abuse and poor self-care.** Nine of the HCPs raised concern that alcohol abuse often contributes to increased seizure manifestation and poor adherence to medication (Q22). Challenges encountered in managing PWE included poor habits such as “they use alcohol heavily”, “sitting in the sun”, “sleep deprivation, stress and videogames” and in lower socio-economic status (SES) groups “they don’t have enough to eat”.

#### 3.3.4 *Macrosystem*

**Impact of ES diagnosis on patient.** Eight HCPs mentioned driving restrictions as the main limitation for PWE. This was described as restrictive not only for young people who “want to drive, independence is their life” but also for securing employment (Q23).

### 3.4 *Theme 4: Knowledge*

#### 3.4.1 *Microsystem*

**Lack of GP collaboration with specialists.** The three specialists in the study expressed their frustration at the lack of communication from the GPs and indicated that they would prefer the GPs to “just pick up the phone and call me” (Q24). They continued to explain that this lack of interaction might result in “sub-therapeutic doses”, “lack of proper management of high-risk patients”.

#### 3.4.2 *Mesosystem*

**Recognition of multiple causes.** Seven of the HCPs described the most common aetiological factors in Namibia as “head injury”, “birth asphyxia and genetic factors”, “congenital birth defects, perinatal problems, early life infections, stroke and neoplasms”. One GP and the two neurologists mentioned neurocysticercosis and parasitic infections as “the most common cause of epilepsy” (Q25).

#### 3.4.3 *Exosystem*

**Need for HCP education.** Five HCPs highlighted the need for increased education of professionals involved in the diagnosis and treatment of ES by stating that more education is needed for GPs “in the management of neurological disorders” (Q26). A statement by a neurologist that “doctors are notoriously poor or deficient at diagnosing epilepsy, especially the more subtle epilepsies which are very difficult to diagnose” highlighted this.

#### 3.4.4 *Macrosystem*

**Need for public education.** Eight HCPs suggested that public knowledge regarding ES should be increased to de-stigmatize the disorder as “it’s a disease that in most African cultures is frowned upon” and “will make it easier to cope with PWE” (Q27).

**Failure to seek treatment due to cultural beliefs.** Nine of the HCPs expressed concern that cultural beliefs may delay or interfere with appropriate treatment (Q28). Explanations raised by the HCPs included “they think they are bewitched, or that somebody had poisoned them” and “spiritual gods, jealousy or curses”. Participants indicated that THPs “tell them to stop the medication” and “that they get prayed on” or “use home remedies”.

**Lack of knowledge contributes to stigma.** It appeared that HCPs were divided on the issue of stigma, with some HCPs indicating that “there is not so much of a stigma anymore” while others felt that “there are a lot of connotations and stigma associated with the illness”. However, nine of the HCPs agreed that PWE may struggle with “social integration” and that “people don’t like to see abnormal movements they don’t want to deal with that” (Q29).

*Negative impact of SES.* Five of the HCPs described that people with lower SES often “have poor levels of education, and are less socially integrated in terms of occupation and marriage”. The participants continued to explain that these patients often encounter unique challenges when diagnosed with ES, such as “not having enough to eat”, and “lack of funds to pay for medication” (Q30).

#### **4. Discussion**

A strong reliance on GPs to diagnose and treat ES, a lack of adequate state healthcare and an overarching belief in the supernatural combine with a lack of knowledge regarding ES and poor socio-economic conditions to paint a beleaguered picture of ES in Namibia. This is in keeping with the sentiment that inefficient healthcare systems, widespread poverty and unevenly distributed material resources are endemic to resource-poor countries [5].

Central to the discussion of the experiences of HCPs in the management of ES is the lack of public knowledge about ES in lower SES groups. This results in failure to seek appropriate and timely treatment due to supernatural beliefs and stigma. This replicates the findings of a study among PWE in Zambia [23]. In the ‘diagnosis’ theme, HCPs stressed the importance of extensive history taking and gathering collateral information prior to arriving at a diagnosis [24]. However, the impact of a lack of knowledge is reflected in parents’ denial when a child is diagnosed with ES. Furthermore, a lack of financial resources prohibit access to specialists and specialised equipment that inevitably leads to PWE being forced to seek care from distant and under-resourced state medical facilities [25,26].

In the ‘treatment’ theme it was evident that HCPs manage the physical symptoms of ES with AEDs and attempt to refer patients to state medical facilities, but their lack of knowledge regarding the psychosocial impact of seizures results in minimal referral to psychologists. An HCP who only focuses on the treatment of the patient’s physical symptoms and who does not consider the patient’s cultural beliefs and emotional disturbance, may create discontent and cause the patient to seek help from other service providers who are more willing to engage with the patient’s emotional grievances [27]. This becomes evident in the ‘patient’ theme with negative

reactions to a diagnosis of ES, poor adherence to medication and health-seeking behaviour resulting in regular use of THPs in an effort to find absolution [28]. Lack of knowledge is again reflected in the subthemes of alcohol abuse and poor self-care where ES-related injuries such as burns and motor vehicle accidents are the most prevalent [29].

Similar to a study conducted in Ghana, HCPs indicated their willingness to accommodate THPs in the treatment of seizures, albeit dependent on the successful regulation of THPs in Namibia [30]. HCPs also acknowledged that increased training and education of GPs and other healthcare workers might improve epilepsy care [31]. The most salient theme throughout this study centred on the lack of knowledge regarding ES, especially in the public domain. The introduction of public awareness campaigns aimed at reducing stigma, fostering acceptance and increasing knowledge about ES may contribute to improved patient management, as is evident from a study conducted in Rwanda [32].

This is the first study of its kind in Namibia and may serve as a departure point for future research on conditions in state healthcare facilities, the health seeking behaviour of PWE and more effective management of ES.

## **5. Limitations**

The sample consisted of HCPs currently in private practice and did not include professionals in full-time government employ. However, some of the specialists consult for the government and five of the GPs have been employed by the government in the past. A further limitation is that HCPs were recruited from the three most central towns in Namibia and may therefore not represent providers across the whole country.

Second, the pool of HCPs was dominated by GPs, with only three specialists participating. This may be ascribed to the lack of specialists in Namibia and the reliance on GPs to serve the bulk of the population. It is regrettably a true reflection of the current situation in Namibia.

Although copies of transcripts were e-mailed to all the participants, the accuracy of interview transcripts was verified by only six HCPs. This may be attributed to time constraints on the side of the HCPs. However, member checks were used during the interviews to clarify the information and to address any misunderstandings or inconsistencies.

## **6. Conclusions**

The exploratory nature of the study paves the way for future research on HCP experiences in developing countries such as Namibia. The study illuminated the significant role of cultural beliefs and THPs in the management of seizures in Namibia [28]. In an effort to understand the role of culture in the manifestation, explanation and treatment of ES, we are currently conducting a study to explore the experiences and roles of traditional and faith healers and how seizures are customarily perceived and treated in non-western cultures. A study of this nature may address the knowledge gap between traditional and conventional healthcare providers in an attempt to improve quality of care to ES patients.

### *Declaration of interest*

Conflicts of interest: none

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## Chapter 7: Manuscript 4

**Title:** Seizures in Namibia: A study of traditional health practitioners

**Authors:** Anina du Toit & Chrisma Pretorius

**Brief Summary:** In this full research article, we report the findings from semi-structured interviews conducted with THPs. This qualitative study focused on exploring how seizures are conceptualized and treated by THPs in Namibia. Thematic analysis was used to identify the four main themes and related subthemes. It was evident during the analysis of the interviews that the perceptions and frustrations of HCPs centred on the areas of diagnosis, treatment, patients and awareness. The four systems of the ecological systems theory were used to conceptualize the discussion of the subthemes and findings were linked to the existing literature on THP practices in Africa. We also discuss the implications of the findings, limitations and suggestions for future research.

**Status:** As of 4 September 2018, the article had been confirmed as available online in *Epilepsia Open*.

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## Seizures in Namibia: A study of traditional health practitioners

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### SUMMARY

**Objective:** Countries in sub-Saharan Africa are plagued by poor healthcare facilities, lack of specialist care, and limited financial resources. People with seizures often rely on the help of traditional health practitioners (THPs). Traditional health practices are not acknowledged in Namibia and remain unregulated and open to exploitation. We conducted a qualitative study to gain an understanding of THPs' perceptions and experiences in delivering seizure care in Namibia.

**Methods:** This study formed part of a larger mixed-method study that explored seizure care among healthcare providers (HCPs) in Namibia. Semi-structured interviews were conducted with 11 THPs in Namibia. Thematic analysis was used to identify themes and subthemes in the data. Themes were interpreted using the different levels of Bronfenbrenner's Ecological Systems Theory to illustrate the perceptions and experiences of THPs in the management of seizures.

**Results:** THPs distinguish between seizures with physical causes and those caused by witchcraft, evil spirits, and supernatural forces. THPs acknowledge the role of Western medicine in the treatment of medically explained seizures (physical causes). Seizures as a result of medically unexplained symptoms (spiritual) are deemed best treated by traditional medicine (TM). Diagnostic and treatment practices are person-specific and are guided by divination and the use of plant and animal material. Treatment success is measured by the complete absence of seizures. Biomedical treatment is seen as lacking due to its focus on seizure control and failure to provide a permanent cure.

**Significance:** In countries with limited healthcare resources, the untapped potential of THPs may play a valuable role in bridging the treatment gap for seizures. Incorporating THPs into the healthcare system depends on proper regulation and clear demarcation of roles between service providers. Improved referral practices and collaboration between service providers will be of benefit for people with seizures who are often exposed to stigma and discrimination.

**KEY WORDS:** Namibia, Sub-Saharan Africa, Epilepsy, Traditional healers, Seizures, Qualitative.

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Anywhere between 65 and 70 million people worldwide live with epilepsy as an everyday reality. About 80–90% of these affected persons live in developing countries.<sup>1,2</sup> In sub-Saharan Africa (SSA), Epilepsy is the single most common, chronic, and severe neurologic disorder. It holds enormous costs, mortality, stigma, seizure-related disability, and comorbidities that the systems in these countries have to address.<sup>3,4</sup> Many of the SSA countries fall into the World Bank's classification of low and lower middle income countries (LMICs) based on gross national income per capita. As such, these countries do not have the resources to handle the

### KEY POINTS

- Traditional health practitioners (THPs) distinguish between medically explained and medically unexplained seizures
- There is a strong belief that medically unexplained seizures are caused by witchcraft, evil spirits, and supernatural causes
- Diagnostic and treatment practices for seizures are individualized and unique to each person
- THPs recognize the role of Western medicine in the treatment of seizures originating from physical causes (medically explained seizures)
- There is a need to acknowledge and regulate traditional health practices in Namibia

immense economic, medical, and social burden that epilepsy brings.<sup>5</sup> Resource-poor countries often have inefficient healthcare systems, widespread poverty, and unevenly distributed material resources.<sup>5</sup> The sparse financial resources serve as a stumbling block to accessing specialists and specialized equipment. People with seizures often have to seek care from distant and underresourced state medical facilities.<sup>6,7</sup>

Traditional medicine (TM) is actively used to address the healthcare needs of approximately 80% of the population in Africa, partly because medical care is so problematic.<sup>8</sup> The accessibility of traditional health practitioners (THPs) in Africa makes them an alluring option in places where there is a lack of skilled medical doctors.<sup>5,9</sup> In addition, the THPs ascribe to a healthcare model that is closer to that of the communities they serve. Most healthcare providers (HCPs) are trained in biomedicine, which is based on the dominant model of disease in Western culture. In Namibia, many people with seizures may first seek treatment from a biomedical HCP, although a diagnosis of an incurable but controllable disease is often deemed unacceptable and prompts people to seek treatment from a THP.<sup>10</sup>

An overview of the TM situation in the African region reports that 39 of 46 countries in Africa have National TM offices and 24 have TM programs in their Ministries of Health.<sup>11</sup> Namibia, Botswana, and Algeria are the only countries in this region for which no information is available.<sup>11</sup> At the moment, THPs in Namibia, many of whom hail from other African countries, have no legally defined status. Prior to Namibia's independence, TM was outlawed in the country.<sup>12</sup> Since its legalization in 1990, several attempts have been made to regulate and formalize the practice of TM. One such an attempt was the establishment of the Namibia Eagle Traditional Healers Association (NETHA) in 1990 with the aim to professionalize and organize THPs.<sup>10,12,13</sup> However, this organization and others of its kind seem to have gone to rack and ruin, and no recent information on its activities are available. The Traditional

Health Practitioners Bill, which was tabled in the National Assembly in 2014, is yet to be promulgated, and the status of THPs in the country remains unclear and unregulated.

Notwithstanding these challenges, the practice of TM seems widespread throughout the country, with last known estimates putting the number of active THPs at 2,400.<sup>14</sup> A pilot study conducted in Windhoek and neighboring Katutura found that THPs play a major role in primary health care and social welfare among the disadvantaged population in Namibia.<sup>13</sup> In Namibia, very little is known about THPs' knowledge regarding the management of seizures, save for 2 studies performed by anthropologists approximately 2 decades ago. This study is a first for Namibia and provides some information about THP practices and the ways in which they diagnose and treat people with seizures. This study may also contribute to some of the objectives of the World Health Organization's Traditional Medicine Strategy<sup>15</sup> by providing insight into the current state of TM in Namibia.

## METHODS

### Data Collection

This study forms part of a larger study that investigated the perceptions and frustrations of biomedical healthcare providers regarding the management of psychogenic nonepileptic seizures<sup>16</sup> and the diagnostic and treatment practices for psychogenic nonepileptic and epileptic seizures in Namibia.<sup>17</sup> There is currently no official regulating body for traditional healers in Namibia, but it does seem that 2 informal organizations in Namibia, namely the Namibian Traditional and Spiritual Healers Association (NTSHA) and NETHA have attempted to play some regulatory role among THPs. However, they do not seem to be in existence anymore and the researchers could not succeed in contacting them for participation in this study.<sup>13,18</sup> Snowball sampling was therefore used to identify possible THPs who would be prepared to participate in the study. The Stellenbosch University Health Research Ethics Committee granted ethical approval for this study (protocol number: REC-050411-032). Data collection took place between June and August 2017.

The first lead on a healer came via an Oshivambo friend. This healer supplied a telephone number of one other healer, who in turn supplied the researchers with a list of other healers and telephone numbers. Many of the numbers were unreachable, but some worked and we were able to arrange meetings with some of them. These healers again provided names of other THPs who was contacted with varying degrees of success. Some agreed to participate subsequent to a telephone call, whereas others were skeptical and appointments were often not kept or the THP could not be reached on the day of the appointment. Possible participants were invited telephonically and the purpose of the study was explained verbally. During this

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process, 36 THPs were identified as possible participants. Telephonic contact was made with 21, appointments were scheduled with 16, and successful interviews conducted with 11. See Table 1 for demographic information on participants.

If the THP agreed to take part in the study, a meeting was arranged at a time and place that suited the THP. All the participants were met at their homes. In some cases, we were accompanied by a healer who had good command of the English language and who was able to assist in clarifying some of the terms used during the interviews. Semi-structured interviews consisted of broad, open-ended questions that explored how seizures are customarily diagnosed and treated by THPs, as well as local beliefs regarding the cause of seizures (Table 2). The total number of interviews depended ultimately on theoretical saturation, and by the 11th interview, various themes started repeating themselves and no new information was emerging.<sup>19</sup> Interviews lasted 30 minutes in some cases and up to 2 hours or more in others.

**Data analysis**

The same analytical strategies and measures to ensure trustworthiness were used as described in a study by du Toit and Pretorius.<sup>16</sup> Qualitative data from the semi-structured interviews were evaluated using thematic analysis (Table S1).<sup>20</sup> The worthiness of qualitative research is often evaluated using criteria such as validity and reliability applicable to quantitative research.<sup>21</sup> As an alternative, the concept of “trustworthiness” is used by qualitative researchers to describe the virtues of a study outside of the parameters that are ordinarily used in quantitative research.<sup>22</sup> Toward this end, Guba<sup>23</sup> proposes 4 criteria that should be considered in a trustworthy study, namely, credibility, transferability, dependability, and confirmability. Peer debriefing, peer examination, and member checks were used to ensure that the data were represented fairly and truthfully.<sup>21,24</sup> To ensure that the study truly reflects the informants’ perceptions and excludes the beliefs and biases of the researcher,

reflexivity and triangulation were used.<sup>25,26</sup> See Table S2 for the processes used in maintaining trustworthiness.

**Theoretical framework**

Bronfenbrenner’s Ecological Systems Theory (EST)<sup>27</sup> was combined with a mixed inductive approach to describe the perceptions and experiences of THPs in a holistic manner by interpreting the ideas and understanding they have of seizures, themselves, and their environments. According to Bronfenbrenner’s EST,<sup>28</sup> human behavior can be considered in terms of a hierarchy of related systems with interactional patterns between and within the systems.<sup>29</sup> Bronfenbrenner describes it as “a nested arrangement of structures, each contained within the next.”<sup>27</sup> The EST is used in the present study as it enables one to describe how the perceptions of THPs could influence the various interrelated systems that form part of the diagnosis and treatment of seizures. Four levels of interaction are outlined in the EST,<sup>27</sup> namely the micro-, meso-, exo-, and macrosystems. The microsystem can be described as the pattern of the activities and the interpersonal relationships of a person who assumes a specific role in a particular place, with another person in a face-to-face setting.<sup>27,30,31</sup> The mesosystem refers to the linkages between the various microsystems in which the THP participates and can be described as a system of microsystems.<sup>28</sup> The exosystem can be seen as an extension of the mesosystem and includes both formal and informal social structures that influence and delimit the person, even though these structures do not directly contain the person.<sup>27,31</sup> The macrosystem refers to the wider societal and cultural norms, such as policies regarding health and economic standards, legal and political systems, attitudes and belief systems, as well as cultural values.<sup>27,31</sup>

**RESULTS**

Results and direct quotes from the thematic analysis are illustrated in Figure 1 and Table 3. Main themes identified during thematic analyses center on diagnosis, treatment,

**Table 1. Demographic information of participants**

P	Age	Gender	Ethnicity	Type of healer	Years in practice
1	69	F	Damara>Nama	Traditional	39
2	72	F	Oshivambo	Traditional	51
3	59	F	Afrikaans	Religious	7
4	66	F	Herero	Traditional	39
5	73	M	Oshivambo	Herbalist/Spiritualist	26
6	42	M	Herero	Spiritualist	21
7	40	M	Herero	Traditional	30
8	46	M	Herero	Traditional	27
9	50	M	Herero	Traditional	35
10	30	M	Nyanja	Diviner	8
11	65	F	Afrikaans	Spiritualist/Diviner	12
	Mean 55.6	M: 55%	6B;2M;7W		Median 27

P, participant; F, female; M, male.

**Table 2. Questions that were used to guide the interviews**

Number	Questions
1	What do you classify as a seizure and what do you think are the possible causes?
2	How do you explain the seizures to the patient and what is their reaction?
3	How do you treat seizures? How successful is it?
4	What kind of contact do you have with Western doctors or hospitals and do you think Western medicine can work for seizures?
5	In your opinion, what problems do people with seizures experience?

patients, and knowledge. Subthemes are reported according to the 4 levels of the EST.

### Theme 1: Diagnosis

#### Microsystem

*Person-specific diagnosis guided by divination.* Ten of the THPs indicated that supernatural forces guide them in determining the cause of a person's illness. The instructions received from divination are combined with the information that the person provides on other illnesses, family history, and an explanation of the seizures in order to arrive at a diagnosis (Q1). In 6 instances, participants mentioned that even when an initial diagnosis was provided at a hospital, the spirit would provide guidance on the specific cause of the seizure in this person.

#### Mesosystem

*Distinguish between spiritual/medical causes.* THPs clearly distinguish between medical and spiritual causes for seizures (Q2). Medical causes can be treated at the hospital as described by one THP (Q3). However, if seizures originate as a result of spiritual causes such as witchcraft, evil spirits, or inheritance, it is believed that they can only be treated by THPs (Q4).

#### Exosystem

*Role of family history in causation.* Six of the THPs mentioned that seizures can be inherited from the forefathers and can be "passed down from generation to generation." Although some described it as a "gene disease," others indicated that participation in witchcraft and demonic activity can lead to seizures among family members (Q5).

#### Macrosystem

*Ineffectual diagnosis by the Western medical system.* THPs stated that HCPs often fail to understand the underlying cause of the seizures and this prevents them from successfully treating the person (Q6). THPs recognize HCPs' efforts; however, they are seen as fruitless when seizures occur as a result of spiritual causes (Q7).

### Theme 2: Treatment

#### Microsystem

*Person-specific treatment guided by divination.* Treatment for seizures is unique to each person and is always guided by what the spirits reveal about the person and the cause of the illness (Q8). Each THP employs different rituals and herbal preparations during treatment as advised by the spirit (Q9). Other practices include the use of plant materials, insects, healing prayers, and laying of hands. Four of the THPs distinguish between treatments for children, elders, and types of seizures (Q10).

#### Mesosystem

*Outcomes-based measure of success.* All the healers claimed that once they treated a person, seizures are completely healed. Success is measured by the complete absence of seizures as reported by the person themselves (Q11). Nine of the THPs stated that the person is healed immediately, whereas 2 indicated that successful healing depends on how long the person has been sick (Q12).

#### Exosystem

*Bi-directional referrals between the state and THPs.* THPs explained that they have an open and collaborative relationship with the state hospitals and will refer a person to the hospital if they are unable to treat the seizures (Q13, Q14). At the same time, THPs stated that they regularly receive people with seizures, either by direct- or self-referral from the hospital. In some cases, doctors informed the person that they cannot be helped or people feel that the medical treatment failed to cure the seizures.

#### Macrosystem

*Western medicine treats symptoms but does not focus on cure.* The perception that seizures are cured only when completely absent is reflected in THPs' statements that Western medicine can only control the seizures, but does not offer a cure (Q15, Q16).

### Theme 3: Patients

#### Microsystem

*Accommodating the patient's explanatory model of illness.* THPs indicated that they rely on the person's narrative and explanation of how and why the seizures may have started (Q17, Q18).

#### Mesosystem

*Attribution grounded in family and community belief system.* Seizures are attributed mainly to witchcraft, evil spirits, and demonic activity. It is believed that seizures can be contracted through food and drinks that were contaminated by magic powers. Other, less magical causes are also

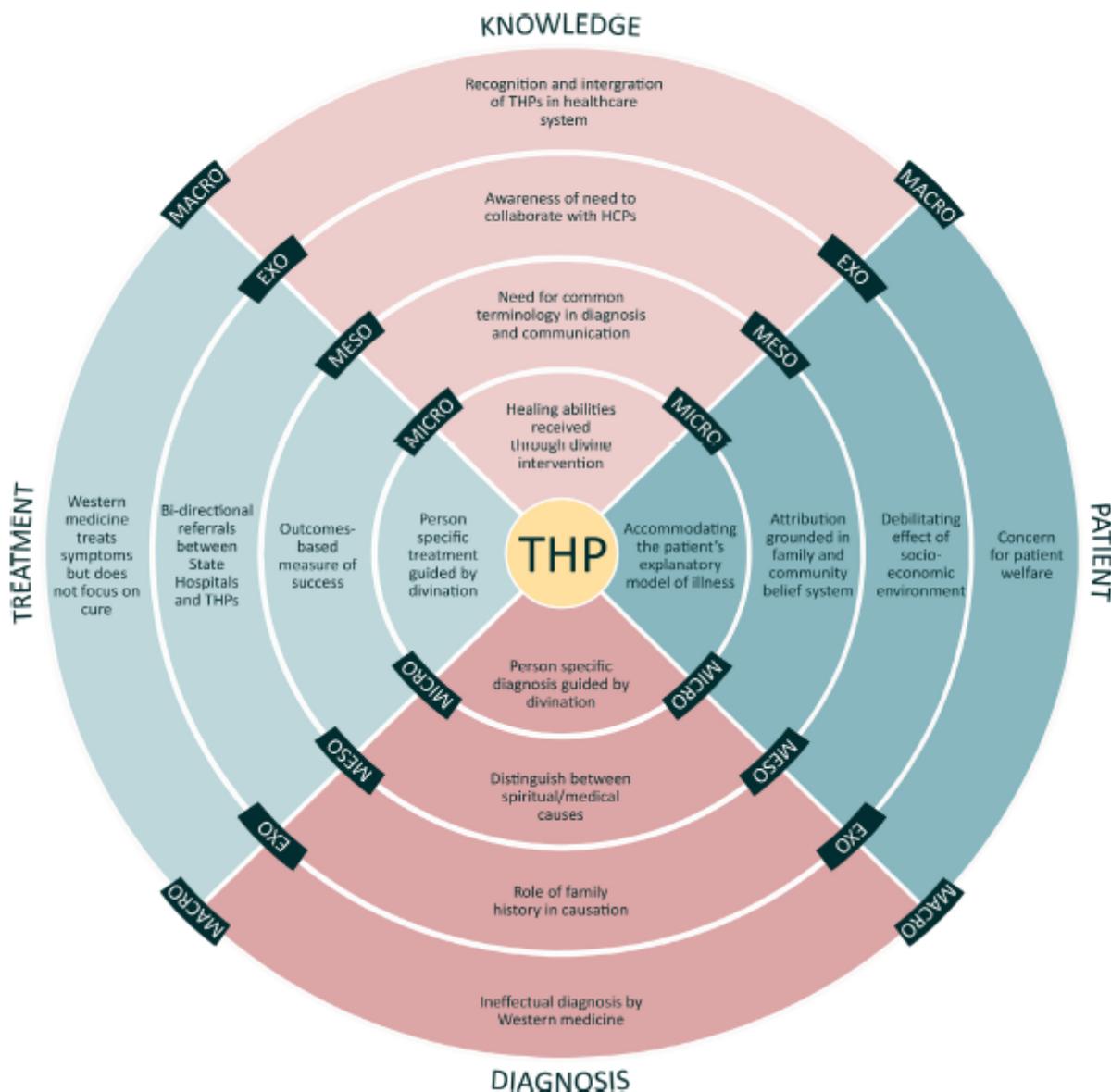


Figure 1.

A graphical illustration of the main themes and subthemes according to the different levels of the Ecological Systems Theory. *Epilepsia Open* © ILAE

considered, such as infections, traumatic brain injury, and various psychological factors (Q19). All the THPs regard mass hysteria, where groups of people experience seizure-like symptoms when exposed to a common stressor to be the work of evil spirits, demons, and witchcraft.

#### Exosystem

*Debilitating effect of socioeconomic environment.* Poor socioeconomic conditions are described as a contributing factor in seizure manifestation (Q20). THPs mentioned that

lack of access to food, poor maternal habits during pregnancy, and alcohol abuse negatively affect the well-being of people with seizures.

#### Macrosystem

*Concern for patient welfare.* THPs expressed concern that people with seizures often encounter unique challenges that affect their quality of life (Q21). Apart from the inability to secure gainful employment, the person may also require constant care from family members (Q22).

Table 3. Emergent main themes and illustrative quotes

Main theme	Illustrative quote
Diagnosis	<p>"I ask for their medical history and I also look to the Bible for guidance. Once it has been revealed that it is epilepsy I tell them the revelations given to me by the Holy Spirit. I explain to them what it is and that it is an evil spirit not sent from God and how I will be treating them." (Q1)</p> <p>"It can be spiritual or it can be medical. If it is medical, it means that the individual is able to go for treatment and then the doctors are able to heal the person through medication. By spiritual I mean, it's a demonic occurrence depending on a person's background." (Q2)</p> <p>"If the epilepsy is from a car accident it is treated by the medical doctors." (Q3)</p> <p>"If the epilepsy is from the witchcraft it is not for Western medicine." (Q4)</p> <p>"Some people come from families where there is deep demonic involvement like witchcraft, where somebody is maybe jealous of a person and they get bewitched." (Q5)</p> <p>"The doctors can't see any problem with them, so they've been lying in a hospital for such a long time without having been helped because doctors can only treat people when they know what exactly happened with this person. If the doctor doesn't know exactly what happened they evict them from the hospital and then they tell them to go to the traditional healer." (Q6)</p> <p>"Doctors are doing their best, but there are some cases which are beyond medical science which now becomes spiritual." (Q7)</p>
Treatment	<p>"The treatment is not purely for each and every person the same, it depends on the guidance of the spirit." (Q8)</p> <p>"Steaming with some herbs that I put in the water or I normally induce vomiting by giving them some herbs from the field." (Q9)</p> <p>"Whether it is the one where it is biting the tongue, or for one that was nearby the fire, or for children up to 10 years." (Q10)</p> <p>"Oh yes it really, really works. I know because the patients come back to tell me that the treatment worked and they normally stop having seizures. All of those that I treated do come back and tell me." (Q11)</p> <p>"Treatment depends on how long this sickness took to get into the body. Up to 2 weeks or 2 months, depending on the person." (Q12)</p> <p>"If it is difficult for the epilepsy to be removed by us, then hospital is a priority or for proper verification that a person is really healed." (Q13)</p> <p>"Doctors and the traditional healers work in conjunction. We work together so the patient will tell the doctor that I am coming from a traditional healer or that I am going to go to a traditional healer. It is no secret." (Q14)</p> <p>"This of witchcraft and inherited cannot be treated by hospital medicines because the hospital gives tablets and medicines, but they don't help 100 per cent and the tablets are not for curing. It's just to make it better." (Q15)</p> <p>"The medication they get usually just subsides the symptoms, but they don't totally heal the disease." (Q16)</p>
Patients	<p>"The person is the only one that will know how he got that epilepsy. Maybe it is an inherited disease from ancestors." (Q17)</p> <p>Disobeying of the commandments, so the person is punished by God, thinking too much or magic powers passed from people." (Q18)</p> <p>"Epilepsy comes from witchcraft, to be bewitched. Or when the baby falls down from the bed, swelling in the brain. The other sort come from depression. Once you have overloaded with many problems. Boyfriends, girlfriends, lifestyle and these type of things, so you become depressed. The other type comes from the environment like evil spirits. When we face years of drought or rain, those years you can get more people that has epilepsy during a particular year." (Q19)</p> <p>"The black community are not living in a conducive environment in terms of food and the water that we are drinking and sanitation. It is something that people should avoid for them to get rid of the disease. If people are hungry or thirsty, or if they drink too much it also brings the epilepsy." (Q20)</p> <p>"I think it does affect their progress in life. People are not able to get job interviews and are not able to work for a long time because of such seizures." (Q21)</p> <p>"When they get this attack during the night when they are sleeping and they are maybe alone, they may die due to respiratory problems." (Q22)</p>
Knowledge	<p>"I got it at birth because I came out feet first and I was wrapped up in the placenta, but it was not my placenta. It was just a cover. So it was a special birth because I came out feet first, I was protected and I have a twin. So in our tribe that is a very strong spiritual kind of birth. Once a person is born like that that it is obvious that he is a healer, that he has a spiritual gift." (Q23)</p> <p>"A seizure is like a fit which a person can get and it can become so bad that the person even urinates and falls down. They don't know where they are and what happened. There is crying and they make a noise and one can see it in the eyes." (Q24)</p> <p>"Such as ones that occur when you are sleeping, others occur when you are hungry and thirsty. Some occur while you are walking down the street and you fall down and have a fit. Another one is when the person is under heat (fever) or finally, a person is born with it." (Q25)</p> <p>"There must be a kind of referral system from the healer to the hospital because sometimes this disease is for the medical doctors. The healers also need to be trained and told that they refer them back to the hospital if it is difficult to treat the epilepsy." (Q26)</p> <p>"Some of the medicine from the Western doctors also work for epilepsy because the spirit says so." (Q27)</p> <p>"Your doctor has to tell you to stop the medicine" and "We encourage them to go to the doctor or for the follow-ups." (Q28)</p> <p>"The only thing that can rectify this epilepsy from the community is if the hospital or the hygienic medical doctors can acknowledge that here in the black communities, our people can heal the disease and then refer those people to the black healers. It will most probably help." (Q29)</p> <p>"They don't have papers. They scramble the people's heads and they ask a lot of money. They take everything that the people own like TVs and furniture. It's a robbing business that." (Q30)</p> <p>"Some of these healers are not entirely honest and sometimes they hurt the people. Some are really bad. It's a money problem but there are lot of impostors." (Q31)</p>

**Theme 4: Knowledge***Microsystem*

*Healing abilities received through divine intervention.* None of the THPs interviewed mentioned that they received formal training or apprenticeship in their field of expertise. Instead, the THPs indicated that they received the gift of healing through divine intervention, which in some cases included extraordinary events during their births or being selected through the spirit of God or inheritance from their family (Q23).

*Mesosystem*

*Need for common terminology for diagnosis and communication.* THPs described the most common signs of seizures as tongue biting, loss of bladder control, and falling down (Q24). A distinction is also made between various types of seizures based on presentation or perceived cause (Q25).

*Exosystem*

*Awareness of need to collaborate with HCPs.* THPs acknowledged that there is a need to collaborate with doctors at the hospital (Q26, Q27). THPs further indicated that they advise people to continue taking medicine prescribed by the hospital (Q28).

*Macrosystem*

*Recognition and integration of THPs in the healthcare system.* THPs expressed the desire that their role in providing services to especially the black community, should be recognized by Western doctors (Q29). Probably the biggest concern for 8 of the healers stemmed from the lack of official regulation of THPs in Namibia. Participants frequently mentioned that healers from other countries mislead the public and demand exorbitant fees for their services (Q30). THPs also raised the concern that impostors may hurt people (Q31).

**DISCUSSION**

More than 60% of the total Namibian population of 2,459,000 rely on public health care provided by the Namibian government.<sup>32</sup> However, economic limitations prevent already underresourced state healthcare facilities from coping with healthcare demands. Given the vastness of the country and its low population density, healthcare facilities are often located in more populated areas, which results in long traveling and waiting times to reach clinics. For this reason, THPs play an important role in healthcare provision to the poor rural communities of Namibia.<sup>33</sup> This is consistent with findings from other studies in Africa that highlight the important role of THPs in rendering culturally inclusive services to local communities.<sup>6,34,35</sup>

Healthcare providers in Namibia recognize that more collaboration is needed with THPs in the treatment of seizure

disorders.<sup>16</sup> This comes with the realization that modern medical treatments sometimes fall short in addressing the healthcare needs of people with seizures in Africa. This is consistent with findings from other studies conducted in African countries that describe the role of THPs in the treatment of epilepsy and mental disorders.<sup>36,37</sup> In this context, it is clear why people with seizures may seek help from THPs who are familiar with local cultural beliefs and who are often more physically and conceptually accessible. Studies in Africa have shown that THPs play an integral role in the treatment of epilepsy.<sup>6,34,38–40</sup> Despite this evidence, THPs' role in the treatment of seizures in Namibia remains unrecognized and their practices unregulated. This leaves an opportunity for THPs from other countries to exploit an already vulnerable population, as people with seizures in Africa are often exposed to stigma, poverty, food insecurity, physical vulnerability, and various forms of abuse.<sup>41–44</sup>

The THPs who participated in this study all believed that seizures can be attributed to the work of evil spirits, witchcraft, and supernatural forces, which is consistent with findings from other studies conducted in South Africa, Zambia, Tanzania, and Kenya.<sup>4,6,34,38</sup> They do, however, make a distinction between medical seizures, which can be treated by Western medicine, and spiritual seizures that can be treated only by THPs. A study among healers in South Africa reported similar findings where participants provided diverse biomedical and local cultural explanations as to the causes of epilepsy.<sup>38</sup> A distinction is therefore made between seizures as a result of identifiable physical causes and seizures that originate as a result of psychological or spiritual causes. This understanding corresponds to the biomedical view of seizures as either medically explained (MES), such as epilepsy, or medically unexplained (MUS), such as psychogenic nonepileptic seizures (PNES). This raises the question of whether THPs, in their own way, can distinguish between epilepsy and PNES. Should this be the case, it is not surprising that THPs can successfully treat people with seizures when the origin is grounded in spiritual beliefs and where the treatment approach is more culturally appropriate. This is because, according to biomedicine, the treatment for MES seems relatively straightforward with pharmacology in the form of antiepileptic drugs (AEDs) the preferred choice of action in the case of epileptic seizures.<sup>1,45</sup> However, the most preferred and effective treatment for MUS, such as PNES, is found in various forms of psychotherapy.<sup>46</sup> However, psychotherapy in a Western medical sense may not appeal to cultures where talking about the inner self is avoided.<sup>16</sup> Toward this end, HCPs in the larger study indicated that they believed THPs can play a supportive role in the treatment of seizures.<sup>17</sup>

As in other African countries, THP practices focus on the person as an individual with a unique diagnosis and treatment plan guided by divination.<sup>38,39</sup> A typical "treatment session" for THPs does not correspond to the Western concept of 1-hour psychotherapeutic sessions. Participants in

this study explained that even when a healer states that the person was healed “immediately,” it is often after treatment that lasted many continuous hours spent on divination, preparations, and performing rituals. These treatments can sometimes last up to a week and are seen as a single intervention. The use of plant and animal material in seizure treatment is never standardized and is often adjusted and applied depending on the person’s needs and the perceived cause of the seizures. This corresponds to findings from studies performed in other African countries that reported the use of herbs, animal products, and insects during treatment.<sup>6,38,39</sup> Success is measured by the complete absence of seizures, which is again entirely possible if the THP is treating the person for what is known as PNES according to Western definitions. Some of the THPs in this study stated that they can completely “cure” people with seizures. A study conducted in South Africa reported similar findings, with 47% of the participating healers believing that they can successfully treat adults with seizures.<sup>36</sup>

At the same time, THPs indicated that they have an open and reciprocal relationship with HCPs at the state hospitals and that people with perceived medical seizures are frequently advised to seek help from Western doctors. This willingness of THPs to refer patients to Western medical facilities was also apparent in other studies conducted in Africa.<sup>40</sup> THPs also admitted that they seldom interfere in the treatment that was prescribed by the hospital and would even encourage the person to return to the hospital for follow-ups. Even though the THPs stated that they regularly receive people who sought help at the hospital, they did indicate that HCPs sometimes take too long to realize that a person may benefit from THP intervention. Despite these positive renditions of collaboration between THPs and the state hospitals, no formal referral system is in place. Consistent with previous research in Africa and the positive renditions of collaboration between THPs and the state hospitals in this study, the lack of a formalized referral system remains a concern among participants.<sup>33,43</sup> Lack of collaboration between healthcare systems leaves much scope for misunderstandings and unnecessary rotation of people between various service points. Until such time when THPs are formally recognized as legitimate service providers and their role in the treatment of seizures acknowledged, their contribution to health care will not be utilized to the fullest extent in Namibia. Especially in SSA, where the seizure treatment gap is significant and access to healthcare facilities is severely limited, the THPs can play a major role in addressing these shortcomings.<sup>6,35,38</sup> Regulation of this industry and the introduction of formal training opportunities for THPs may address some of the misgivings of HCPs about the role of THPs in health care. This goes hand-in-hand with the clear demarcation of roles and responsibilities and the introduction of proper guidelines for the management of people with seizures.

## LIMITATIONS

This study required that snowball sampling be used to identify possible participants. This leaves the possibility that the sampling method could have led to bias in the sample, as THPs may have identified their peers for participation. The findings of this study are therefore not representative of THPs across the country and cannot be generalized. However, despite these shortcomings and the small sample size of the study, the purpose was to generate depth rather than breadth and the study focused on generating information-rich findings on the perceptions and experiences of THPs in the management of seizures.<sup>47,48</sup>

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## DISCLOSURE

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Table S1. Stages of thematic analysis.

Table S2. Process of maintaining trustworthiness.

## Chapter 8: Discussion and Conclusion

This study aimed to identify the perceptions and frustrations of Namibian HCPs and THPs regarding the conceptualization, diagnosis and treatment of medically explained (ES) and medically unexplained (PNES) seizures in Namibia. The product of the investigations into HCP and THP experiences is reported in four manuscripts, which are included in Chapters 4, 5, 6 and 7 of this dissertation. This chapter integrates the main findings and conclusions of the four manuscripts. First, it provides a brief overview of how the study was conducted. This is followed by an integration of the four manuscripts according to the main themes of the thematic analysis, namely diagnosis, treatment, patients and awareness. Next, it continues to outline the limitations of the study and the interpretation, contributions and implications of the findings. The chapter closes by reflecting on the researcher's experiences and providing concluding remarks.

### 8.1. Introduction

Successfully managing patients who present with seizures can be both costly and resource intensive and efforts from various stakeholders are needed to meet the needs of this population (Cameron et al., 2012; Mbuba et al., 2008). Given that it takes an estimated 7.2 years to reach a definitive diagnosis of PNES, seizures are costly to both the economy and the healthcare infrastructure (Devinsky et al., 2011; Pretorius & Cronje, 2015; Reuber et al., 2002). LMIC countries, based on the World Bank classification of gross national income per capita, are often poorly equipped to deal with the enormous economic, medical and social burden posed by seizures (Radhakrishnan, 2009). The successful management of seizures are, therefore, of extreme importance in developing countries with limited access to adequate healthcare infrastructure and human resources. As a result, it is crucial to determine the diagnostic and treatment options available to people with seizures and to see how the Namibian infrastructure and skills base contend with ES and PNES. Given the lack of skilled human resources, the vastness of the country and its low population density, healthcare facilities are often located in more populated areas, which results in long travelling and waiting times to reach clinics. For this reason, THPs play an important role in healthcare provision in Africa, and specifically in the rural communities of Namibia.

Namibia does not have statistics or diagnostic and treatment guidelines for PNES or ES. This, combined with the goals of the ILAE and ILAE PNES Task Force to gather information on diagnostic techniques and treatment modalities for the management of seizures, prompted the need for the present study in Namibia. In addition, no known studies have been conducted on the diagnostic and treatment modalities used for seizures in a Namibian context. It was against this background that the present study sought to investigate the perceptions and experiences of HCPs and THPs involved in the management of seizure patients in Namibia. The use of a mixed

method design that combined results from qualitative and quantitative approaches made it possible to address the research question by combining information from in-depth interviews with descriptive statistics to present a holistic view of the current management practices for seizures in Namibia.

The present study commenced with an overview of the literature pertaining to seizures, with a specific focus on ES and PNES. Following an outline of the methodology used in the study, the first manuscript, presented in Chapter 4, reported the findings derived from semi-structured interviews with HCPs on their perceptions and frustrations in dealing with PNES. In Chapter 5, the second manuscript offered an overview of the most salient information collected by means of ES and PNES surveys for HCPs. The results from these surveys provided information regarding the current availability of diagnostic and treatment services for seizures in Namibia. This information was used to contextualize the perceptions and experiences of HCPs concerning the management of patients with seizures. The third manuscript was presented in Chapter 6 and focused on the perceptions and experiences of HCPs in the management of ES as reported in semi-structured interviews. Chapter 7 presented the final manuscript, in which semi-structured interviews with THPs provided a view on how seizures are customarily perceived and treated with TM. In the current chapter, the main findings from each manuscript are integrated to answer the overarching research question: “What are the perceptions and frustrations of Namibian HCPs and THPs regarding the conceptualization, diagnosis and treatment of medically explained (ES) and unexplained seizures (PNES) in Namibia?” The findings reported in the various manuscripts are presented here according to the main themes identified during the thematic analysis, namely diagnosis, treatment, patients and awareness. This aids the effort to address the aims and objectives of the study namely to investigate the experiences of HCPs and THPs regarding medically explained (ES) and unexplained seizures (PNES) with a primary focus on:

- the attitudes and beliefs of HCPs and THPs regarding seizure manifestation;
- the nature of conventional diagnostic and treatment services available in Namibia for patients with seizures;
- challenges encountered by HCPs and THPs in the management of seizures;
- post-diagnostic instructions to patients diagnosed with seizures; and
- Inter- and cross-referral practices among HCPs and THPs regarding seizure patients.

Table 8.1 provides an overview of the main themes and subthemes as it was reported in Manuscripts one, three and four.

Table 8.1. *Overview of the main themes and subthemes reported in each manuscript.*

	Manuscript 1	Manuscript 3	Manuscript 4
D I A G N O S I S	<ul style="list-style-type: none"> <li>• The use of basic diagnostic techniques</li> <li>• Diagnosis by elimination</li> <li>• Own lack of experience</li> <li>• Delay in diagnosis</li> <li>• Affordability of healthcare costs</li> <li>• Other HCPs' lack of experience</li> <li>• Lack of access to specialists/equipment</li> <li>• Quicker referral from other HCPs</li> <li>• Role of cultural attribution in causality</li> </ul>	<ul style="list-style-type: none"> <li>• Parental reaction to children diagnosed with ES</li> <li>• Clinical diagnosis by a GP based on collateral info and patient history</li> <li>• Regular referral for diagnostic testing</li> <li>• Affordability of healthcare expenses</li> <li>• Lack of access to specialists/equipment</li> <li>• Availability of state medical services</li> </ul>	<ul style="list-style-type: none"> <li>• Person specific diagnosis guided by divination</li> <li>• Distinguish between spiritual/medical causes</li> <li>• Role of family history in causation</li> <li>• Ineffectual diagnosis by Western medicine</li> </ul>
T R E A T M E N T	<ul style="list-style-type: none"> <li>• Effective therapy is available</li> <li>• Challenges related to therapeutic techniques</li> <li>• Reverting to medication</li> <li>• Indiscriminate use of AEDs</li> <li>• Failure to respond to treatment</li> <li>• Appropriate referral to psychologists</li> <li>• Lack of feedback from referrals</li> <li>• Recognition of the need for multidisciplinary approach</li> <li>• Lack of patient ownership</li> <li>• Lack of access to psychological services</li> </ul>	<ul style="list-style-type: none"> <li>• Importance of seizure control through the use of AEDs</li> <li>• Lack of regular follow-up for AED patients</li> <li>• Minimal referral to psychologists</li> <li>• Impact of drug side-effects on patient adherence</li> <li>• Availability of specialized procedures</li> <li>• Referral to state medical facilities</li> <li>• Willingness to collaborate with THPs</li> </ul>	<ul style="list-style-type: none"> <li>• Person specific treatment guided by divination</li> <li>• Outcomes-based measure of success</li> <li>• Bi-directional referrals between State Hospitals and THPs</li> <li>• Western medicine treats symptoms but does not focus on cure</li> </ul>
P A T I E N T S	<ul style="list-style-type: none"> <li>• Effective communication of diagnosis</li> <li>• Challenges in communication of diagnosis</li> <li>• Need for patient education</li> <li>• Negative patient reaction to diagnosis</li> <li>• Minimal secondary gain as motive</li> <li>• Recognition of family understanding</li> <li>• Familial lack of support and denial</li> </ul>	<ul style="list-style-type: none"> <li>• Incidence of ES related injuries</li> <li>• Negative patient reaction to diagnosis</li> <li>• Poor adherence to medication</li> <li>• Recognition of patients' health-seeking behaviour patterns</li> <li>• Impact of alcohol abuse and poor self-care</li> <li>• Minimal secondary gain as motive</li> <li>• Regular use of THPs</li> <li>• Recognition of family involvement</li> <li>• Impact of ES diagnosis on patient</li> </ul>	<ul style="list-style-type: none"> <li>• Accommodating the patient's explanatory model of illness</li> <li>• Attribution grounded in family and community belief system</li> <li>• Debilitating effect of socio-economic environment</li> <li>• Concern for patient welfare</li> </ul>
A W A R E N E S S	<ul style="list-style-type: none"> <li>• Recognition of own ignorance</li> <li>• HCP ignorance contributes to misdiagnosis</li> <li>• Recognition of multiple causes</li> <li>• Need for HCP education</li> <li>• Availability of training opportunities</li> <li>• Need for public education</li> <li>• Lack of recognition for PNES as valid disorder</li> <li>• Negativity towards mental illness</li> <li>• Failure to seek treatment due to stigma</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of GP collaboration with specialists</li> <li>• Recognition of multiple causes</li> <li>• Need for public education</li> <li>• Failure to seek treatment due to cultural beliefs</li> <li>• Lack of knowledge contributes to stigma</li> <li>• Negative impact of socioeconomic status</li> </ul>	<ul style="list-style-type: none"> <li>• Healing abilities received through divine intervention</li> <li>• Need for common terminology in diagnosis and communication</li> <li>• Awareness of need to collaborate with HCPs</li> <li>• Recognition and integration of THPs in healthcare system</li> </ul>

## 8.2. Integration of the Findings on Diagnostic Techniques and Services

By integrating the findings from all four research investigations performed during the execution of this study, one can form an overarching picture of the most common pathways used for the diagnosis of seizures in Namibia. It was evident from the findings that diagnostic services for seizures are heavily influenced by the level of knowledge that HCPs have regarding MES and MUS. This became clear in Manuscript 2 where HCPs reported a higher level of confidence in making an ES diagnosis compared to a diagnosis of PNES. It was also reflected in the number of patients diagnosed and currently in their care, with ES numbers far exceeding those of PNES. This may be ascribed to the relatively unknown nature of PNES among Namibian HCPs and the fact that a diagnosis of PNES is seldom considered when the HCP is confronted with what looks like physical symptoms. Lack of confidence was also mentioned as a concern in other studies that investigated HCPs' ability to manage PNES patients (Sahaya et al., 2012). However, in conversations with THPs it became clear that these practitioners distinguish between "medical seizures" (MES) and seizures that are caused by "spiritual means" (MUS) right from the beginning. This differentiation is based on the personal history of the patient, extensive explanations from family members as to how the seizures originate and the patient's understanding of the origin of the seizures. Although HCPs mentioned the value of collateral information from observers or family members, it seemed that they often failed to consider the cultural background of the client and how seizures are traditionally perceived in different cultures.

During the interviews with HCPs, it was evident that despite a strong reliance on diagnostic strategies independent of specialized tests, HCPs do make use of specialized diagnostic investigations such as EEG monitoring to confirm or dispute a diagnosis of ES or PNES. In Manuscripts 1, 2 and 3, HCPs lamented the lack of access to specialized equipment and specialists who can confirm the diagnosis. This was combined with a realization that patients often lack the financial resources necessary to undergo such specialized procedures. The alternative in many cases include referral to state healthcare facilities. This in itself is a source of frustration as HCPs described the poor conditions in these facilities (Lipinge, 2006) and the animosity between public and private HCPs. THPs also indicated that they refer clients to state healthcare facilities when they suspect "medical seizures," and by their own accounts it seems that there is a more collaborative relationship between themselves and state healthcare workers than with private HCPs. This willingness of THPs to refer patients to Western medical facilities was also apparent in other studies conducted in Africa (Njamnshi et al., 2010). However, THPs indicated that patients are often incorrectly diagnosed by the "Western doctors" at these facilities, which reflected some of the frustrations experienced by THPs.

In the surveys, it became evident that HCPs rarely refer people with seizures for psychological assessments as part of the diagnostic process, notwithstanding growing evidence that the psychological and social domains have the greatest impact on the quality of life in PWE (Elliott & Richardson, 2014). Although HCPs indicated that they refer patients with suspected PNES for psychological assessment, it did not happen as a rule, but rather as an exception. Only about half of PNES patients are regularly referred for psychological/psychiatric assessment. Similarly, in a study conducted by O'Sullivan et al. (2006), 35 per cent of GPs felt that psychiatric or psychological intervention is beneficial however, 57 per cent did not feel comfortable to make the initial referral. In the present study, the low referral rate for this type of assessment can be traced back to HCPs' lack knowledge about PNES or their perception that few patients can afford psychological services.

The final concern raised by HCPs in the diagnosis of seizures related to the poor collaboration between the various HCPs responsible for a seizure patient. Lack of patient ownership, ineffectual referral practices and the absence of feedback among providers contribute to delays in diagnosis. A lack of collaboration between HCPs seems to be common when it comes to seizure management (Bora et al., 2011; McMillan et al., 2014). In both the ES and PNES interviews, it was found that HCPs see themselves as playing a specific role in the diagnosis and treatment of seizures, but that they seldom communicate with other professionals who may be involved with the patient at the same time. This failure of cross-disciplinary collaboration results in increases in healthcare costs, a lack of patient ownership and feelings of abandonment and uncertainty in patients (McMillan et al., 2014). The same sentiment was raised by THPs who, despite positive renditions of collaboration between THPs and the state hospitals, indicated that misunderstandings and unnecessary rotation of patients result in poor patient management.

### **8.3. Integration of the Findings on Treatment Services and Modalities**

The combined findings from the various manuscripts highlighted substantial differences in how HCPs and THPs approach the treatment of seizures. In Manuscript 4, it was described that THPs focus on the person as an individual with a unique diagnosis and treatment plan guided by divination. In TM, seizure treatment is individualized according to the patient's needs and although it often includes the use of plant and animal material, it also focuses on the spiritual aspects of the disorder (Njamnshi et al., 2010). Looking at responses from HCPs during the interviews, it became evident that seizure control features highly on the agenda of biomedical practitioners. This was reflected in subthemes that described the importance of seizure control and the frequent reliance on AED treatment even before a definitive diagnosis had been made. However, it was found that seizure remission does not necessarily translate to improved outcomes and should therefore not be the main focus of treatment programmes (Reuber et al.,

2005). This state of affairs seemed to cause frustration among some of the HCPs who lamented the indiscriminate use of medication in seizure treatment. At the same time, it reflects the perception that seizures should primarily be treated with biological interventions, which results in a disregard for the psychosocial aspects of the disorder and an exclusive focus on the physical symptoms of the seizures (Blumer, 2008). Whereas biomedicine strives to “manage” the condition, THPs strive to “cure” it. For this reason, THPs believe that Western medicine can only treat the symptoms, but is unable to relieve the patient of the seizures completely, whereas their own treatment success is measured by the complete absence of seizures.

However, the use of medication in the treatment of seizures presents its own challenges. One of the challenges is that although effective AED treatment is available in Namibia, it is not always within the financial reach of patients from lower SES. State medical facilities do supply AEDs, but again, this service is hampered by the reluctance of state healthcare workers to assist patients referred by private HCPs. Another challenge relates to the follow-up of seizure patients in general, but also specifically those on AED treatment. During the semi-structured interviews with HCPs reported in Manuscript 3, regular follow-up for patients on AED treatment were performed by only a minority of HCPs. However, in Manuscript 2, where the results of the surveys were disseminated, ES HCPs appeared to follow up on patients more regularly than PNES practitioners did. This discrepancy may be explained by the failure of PNES patients to respond to AED treatment, the resultant fatigue experienced by HCPs and the finding that HCPs feel more confident to treat ES than PNES. According to the literature, much harm is done by employing aggressive therapies and inappropriate treatments such as the use of AEDs in an attempt to stop seizures in PNES patients (LaFrance Jr. & Blumer, 2010). In fact, most PNES patients receive unnecessary AEDs even though extensive observational data suggest that such treatment is ineffective or may even worsen PNES symptoms (LaFrance Jr. & Blumer, 2010; Reuber et al., 2002). Furthermore, indecision regarding the most suitable treatment method for PNES often results in the perception that it is a difficult disorder to treat (O’Sullivan et al., 2006; Quinn et al., 2010).

This brings the discussion back to the role of psychotherapy in the treatment of seizures and that the most preferred and effective treatment for MUS, such as PNES, is found in various forms of psychotherapy (Krebs, 2007). At the same time, psychotherapy can play an integral part in the treatment of comorbid mental health disorders in PWE (Tang et al., 2014). Despite these findings and the HCPs’ opinion that effective therapy is available in Namibia, it was found that referring HCPs seldom make use of psychologists to treat or support people with seizures. Although this can partly be ascribed to a lack of knowledge about the benefits of psychotherapy, HCPs ascribed their failure to refer to psychologists to the patient’s lack of financial resources and a shortage of psychologists who are familiar with treating patients with seizures. The

possible role of THPs in the treatment of seizures is stressed in Manuscript 1, with the realization that conventional psychotherapeutic techniques may not make adequate provision for the unique cultural beliefs in non-Westernized populations. The THPs who participated in this study all believed that seizures can be attributed to the work of evil spirits, witchcraft and supernatural forces and that they can successfully treat patients when the origin of the disorder is grounded in spiritual beliefs and where the treatment approach is culturally appropriate.

The final treatment option open to patients with ES is surgery or vagal nerve stimulation (Moshé et al., 2015). These procedures are only available in neighbouring South Africa and come with a hefty price tag. HCPs therefore indicated that they seldom refer patients for surgery. They also raised questions about the success rate of these specialized procedures (S. P. Singh et al., 2017).

Faced with the above challenges, HCPs recognized that a multidisciplinary approach is needed to manage people with seizures successfully. However, multidisciplinary collaboration is often compromised due to a lack of coordination and communication between the different disciplines (Baslet et al., 2016; McMillan et al., 2014). HCPs also recognized that some patients prefer to be treated by THPs and they acknowledged that these practitioners might play a supportive role in the management of seizures. However, despite HCPs' willingness to collaborate with THPs, they did indicate their reluctance to refer patients to THPs as the role of THPs is seen as mainly supportive and not as critical to the diagnostic and treatment of seizures. However, THPs perceive their relationship with HCPs at state hospitals to be open and reciprocal, with frequent patient referrals, encouragement to continue medication from Western doctors and advising patients to return to the hospital for follow-ups.

#### **8.4. Integration of the Findings on Patients**

The findings that reflected the patient theme were remarkably analogous across the various manuscripts with similar concerns being raised by both HCPs and THPs, irrespective of seizure type. HCPs involved in the management of PNES, however, did find themselves challenged by their own lack of knowledge about the disorder and this affected their ability to communicate the diagnosis to the patient successfully. Despite this shortcoming, HCPs in both the PNES and ES interviews and the surveys grasped the significance of the manner in which the ES or PNES diagnosis is imparted and what phrases and terminology are best suited to explain the causes and possible treatment to the patient. These explanations showed that HCPs endeavour to minimize the effect of stigma, to assure the patient that the seizures are not deliberate and that it should be taken seriously. In addition, HCPs recognized that it is important for the family to understand the diagnosis in order to increase the likelihood of familial support and to decrease the possibility of using secondary gain as a motive for the seizures. For THPs, the connection between family and the origin of the seizures runs even deeper and seizures are

often attributed to the belief systems held by the family and the community. For these practitioners, the patient's explanations of the illness forms an integral part of the diagnosis and treatment techniques used during seizure management.

However, HCPs found that the effective communication of the diagnosis is often complicated by perceived patient ignorance. However, HCPs and patients frequently have different EMs about illness episodes and the quality of the healthcare interaction depends on the degree to which these EMs are compatible (Bassett, 2011). It is then not surprising that the communication of the seizure diagnosis was further complicated by negative reactions from the patient and family when they firstly fail to understand and grasp the psychological underpinnings of PNES, and secondly fail to understand the impact of ES on the patient's day-to-day life. Differences in illness perceptions between HCPs and patients often lead to misunderstandings and poorer outcomes (Stone et al., 2003). It is therefore of the utmost importance that the relationship between physician and patient is such that the patient is prepared to engage in treatment. However, HCPs indicated that negative reactions to the diagnosis often results in poor adherence to medication and failure to take cognizance of post-diagnostic instructions. In addition, HCPs and THPs stated that patients often continue to abuse alcohol, fail to adhere to appropriate self-care behaviours and engage in activities that increase the risk for injuries.

In discussions with HCPs, it was once again apparent that the focus remained mostly on the physical management of the seizures. However, an HCP who only focuses on the treatment of the patient's physical symptoms and who does not consider the patient's cultural beliefs and emotional disturbance, may create discontent and cause the patient to seek help from other service providers who are more willing to engage with the patient's emotional grievances (Helman, 1981). It is then not surprising that HCPs recognized that patients often seek second opinions from other practitioners and regularly use the services of THPs in an effort to find absolution for their illness (Eastman, 2009). However, both HCPs and THPs raised concerns about the welfare of seizure patients in relation to as the ability to pay for medical services, the ability to secure employment and regular meals, as well as the constant care required from family members.

### **8.5. Integration of the Findings on Knowledge and Awareness**

The pervasive lack of knowledge and awareness about seizures among both the public and HCPs warranted the inclusion of a separate theme that relates only to the topic of awareness. This is to provide an overarching picture of the various perceptions, while simultaneously highlighting the lack of knowledge concerning seizures. This section therefore integrates the findings from the other main themes that relate to knowledge and awareness about seizures, while adding some additional insights unique to this section.

Lack of knowledge about seizures first became evident in discussions about PNES where HCPs acknowledged that they know very little about this disorder. It further became apparent that HCPs are seldom able to differentiate between PNES and ES. Furthermore, knowledge about PNES determines HCPs' perceptions regarding the disorder and a lack of such awareness and knowledge leads to PNES being misdiagnosed by HCPs who do not possess the skills to manage the process of diagnosis and treatment successfully (Farghaly et al., 2013). Although this may be ascribed to a lack of HCP experience and the concomitant unknown nature of PNES, it results in unnecessary delays until a definitive diagnosis of PNES is reached. The impact of misdiagnosis on the lives of patients is well documented and include the unwanted side effects of AEDs as well as the negative impact on psychosocial functioning (Baslet et al., 2016; Guo et al., 2012; Xu et al., 2016). Although most HCPs acknowledged the underlying psychological causes for PNES, the stigma associated with mental and psychiatric disorders presents a barrier to the successful treatment of the disorder (R. Thompson et al., 2009). This may explain why so few HCPs in this study refer seizure patients for psychological intervention. At the same time, the low referral rate for this type of treatment can be traced back to GPs' lack of knowledge about PNES and possible treatment options as well as HCPs' failure to recognize that the psychological and social domains have the greatest impact on the quality of life in PWE (Elliott & Richardson, 2014). Lack of knowledge on the side of HCPs may also explain why GPs continue to prescribe AEDs notwithstanding the fact that it has been shown to be ineffective in the treatment of PNES (LaFrance Jr. & Blumer, 2010). However, most of the above challenges can be ameliorated by accessing the knowledge base of specialists, and yet, the specialists that participated in the study expressed their frustration at the reluctance of the GPs to ask for assistance in the management of seizure patients.

In addition, lack of knowledge and awareness extended to patients, with the effective communication of the diagnosis being complicated by patient ignorance. Although HCPs demonstrated that they are well versed in the appropriate techniques required to communicate complicated diagnoses, challenges arose when the HCP did not possess sufficient confidence and knowledge to guide the patient (Monzoni et al., 2011a; Robson & Lian, 2016). Negative patient reactions and failure to seek appropriate and timeous treatment is further influenced by the lack of knowledge about seizures, stigmatization, cultural beliefs about the supernatural origin of seizures and negative views of mental disorders (Baskind & Birbeck, 2005a). Finally, the impact of the lack of knowledge about seizure disorders can be seen in the failure of patients to adhere to post-diagnostic instructions related to the adverse effects of alcohol abuse, poor self-care and the possibility of seizure-related injuries. In addition, HCPs called for increased seizure awareness among the public as this might modify perceptions about the disorder and encourage PWE to seek timeous treatment (Osungbade & Siyanbade, 2011).

The consequences of the above findings and possible ways to address these are discussed in the section on the implications for clinical practice, policy-making and future research.

### **8.6. Limitations of the Study**

Despite contributing to the advancement of knowledge about the conceptualization, diagnosis and treatment of medically explained (ES) and unexplained seizures (PNES) by HCPs and THPs in Namibia, some limitations of the present study merit consideration.

First, the sample consisted of HCPs in private practice and did not include professionals in full-time government employ. However, some of the specialists and GPs in this study either consult for the government or had been employed by the government in the past. The decision to focus mainly on HCPs in private practice stemmed from information that relatively few specialists are employed by the government (Ministry of Health & Social Services, 2016). At the time of this study, two psychiatrists and two psychologists rendered services for the government at the Windhoek Mental Health Unit at the Windhoek Central Hospital (Ministry of Health & Social Services, 2016). Several attempts were made to contact the psychiatrists at the hospital prior to the commencement of the study, but this proved futile. Thus, it is possible that by focusing on the experiences of HCPs in private practice, the findings might be skewed towards the challenges experienced by a higher income sector of the population. However, at the same time, this illuminates the shortage of specialist physician services in state healthcare facilities (WHO Regional Office for Africa, 2010).

Second, the HCPs who participated in this study were predominantly recruited from the three most central towns in Namibia, although a small number of HCPs from other towns also participated. The sample may therefore not represent providers across the whole country. Notwithstanding this selection bias, this is the first study, to my knowledge, that embarked on a systematic investigation of HCP practices concerning seizures in Namibia.

Third, the samples that focused on HCPs were dominated by GPs. This may be ascribed to the lack of specialists in Namibia and the reliance on GPs to serve the bulk of the population. It is regrettably a true reflection of the current situation in Namibia. Similarly, the pool of HCPs was not homogenous in terms of qualifications and areas of expertise. However, the service providers in the sample do share the commonality that they all play a role in the management of seizures, albeit through the use of different techniques and approaches. The diversity of the group is further reflected in the extent of support received for each of the subthemes in the thematic analysis. HCPs expressed support for themes related to their area of expertise, such as either the diagnosis or treatment of patients, depending on their vantage point. This may explain why few of the themes were supported by the majority of the HCPs.

Fourth, the proportions reported in the ES and PNES surveys were based on HCPs' recollection of patients diagnosed, managed and investigated rather than on actual data. None of the HCPs in this study kept records of actual data or patient encounters and, therefore, relied solely on memory and overall impression. Moreover, in view of the differences in medical care practices, socioeconomic conditions, cultural perceptions and the financial framework in which HCPs practice in Namibia, the findings of this survey cannot necessarily be generalized to other countries, but were used to complement the findings of qualitative studies. However, the result from the PNES survey can be compared to studies conducted in the USA, Chile, UK and Brazil that investigated existing healthcare infrastructure and strategic health practices used for PNES management (LaFrance Jr. et al., 2012; Mayor et al., 2011; Valente et al., 2017, 2015). Findings from the ES survey can be equated to studies that included information on epilepsy care in developing countries (Birbeck, 2010; Dua, de Boer, Prilipko, & Saxena, 2006). Comparisons can therefore be made between the findings of this study and those that examined conditions in other countries insofar as standard medical care for seizures is concerned.

Fifth, the respective response rates of 28.74 and 35.21 per cent in the surveys are consistent with other uncompensated surveys that focused on responses from health service providers. These studies stated a response rate of between 8 and 45 per cent (Valente et al., 2015).

Sixth, although copies of transcripts were e-mailed to all the HCPs, the accuracy of interview transcripts were verified by only ten HCPs. Due to time constraints on the side of HCPs, it was not possible to verify the remaining transcripts. However, member checks were used during the interviews to clarify the information and to address any misunderstandings or inconsistencies.

Finally, the study that focused on THPs required that snowball sampling be used to identify possible participants for the study. This leaves the possibility that the sampling method could have led to bias in the sample as THPs may have identified their peers for participation. The findings of this study are therefore not representative of THPs across the country and cannot be generalized. However, despite these shortcomings and the small sample size of the study, its purpose was to generate depth rather than breadth and it focused on generating information-rich findings on the perceptions and experiences of THPs in the management of seizures (Patton, 1999; Sandelowski, 1986). Copies of transcripts were made available to THPs for purposes of crosschecking and validation. Member checks were used during the interviews to clarify the information and to address any misunderstandings or inconsistencies.

## 8.7. Interpretation of the Findings

In order to make sense of the findings of this study, it is important to return to the original “lens” that was used to study HCP and THP practices in the management of seizures. Bronfenbrenner’s (1977, 1979) ecological systems theory afforded the researcher an opportunity to study the processes in and between interrelated social systems and the HCPs and THPs. I was therefore able to identify how HCP and THP practices a patients, other healthcare professionals and the broader social context but also how these factors affect the HCP and the THP. The HCP or THP as an individual is seen as the centre of the entire system, with the various systems forming permeable and bidirectional layers around the person. The key to this theory lies in the “interaction within the layers of the structures and the interaction of the structures between the layers” (Härkönen, 2007, p. 7). The HCP or THP is made up of various levels of knowledge, skills, self-confidence, perceptions, frustrations and motivations and has different roles that influence the patterns of interaction with and within the different systems (Gregson et al., 2001; McLeroy et al., 1988).

While applying the EST to the findings of this study, it is important to distinguish between the various HCPs involved in the management of seizures in Namibia. For purposes of this discussion, primary care providers include GPs and neurologists, while secondary HCPs include psychologists and psychiatrists. GPs play a pivotal role in the initial diagnosis of seizures in a resource-poor country such as Namibia. Due to a lack of specialists such as neurologists, GPs remain the first port of call for patients who display signs of seizures. According to the findings, access to a neurologist is determined by firstly having the financial resources to pay for an appointment, and secondly being in close proximity or within travelling distance from such a specialist. In this study, it was clear that even though primary care HCPs acknowledge the role of mental healthcare professionals in the treatment of seizures, they seldom refer patients to psychologists and psychiatrists. What was also evident from the discussions with HCPs was that psychiatrists and psychologists are typically seen as playing a supportive or secondary role when it comes to seizure management. The same applied to HCPs’ views on THPs, which was described as possibly supportive and not critical to the diagnostic and treatment process of seizures. Even though patients are free to seek the help of psychologists and psychiatrists, this is unlikely to happen in the case of seizure disorders, especially given the stigma attached to mental healthcare. Therefore, referral to mental healthcare providers is often dependent on the discretion of the GP or the neurologist in charge of the patient (Unützer, Michael, Druss, & Katon, 2006). In this sense, primary care HCPs in Namibia can be seen as the gatekeepers to healthcare.

The above state of affairs in Namibia can possibly be explained by the fact that primary care HCPs are trained in biomedicine, with a focus on the physical causes of disease and where treatment is seen as similar for all individuals (Kleinman, 1978). This view presents two

problems, namely that it is based on the EM of illness according to Western culture and it leaves very little scope for the psychological and social aspects of disease. Explanatory models and psychosocial effects of illness episodes are unique to each individual and differ across ethnic groups and cultures (Kleinman, Eisenberg, & Good, 1978). It is then not surprising that primary care HCPs were often at a loss when faced with a patient whose explanatory model for an illness episode differed substantially from their own. At the same time, HCPs struggled to cope with patients whose symptoms cannot be explained by biological causes and are loathe to consider psychological explanations in such cases (Hatcher & Arroll, 2008). Even in cases where the HCPs in this study were able to identify medically explained symptoms, the psychological and social impact of the illness were deemed to fall outside the scope of their practice. However, one has to recognize that people are multi-dimensional beings, consisting of biological, psychological and social components (Engel, 2012). Healthcare provision should therefore take into account that all these dimensions have to be satisfied for a person to function optimally. Yet, the biomedical view of health addresses a patient's biological needs, and in doing so, treats the disease, but not the whole person.

This being said, one cannot deny the role of primary care HCPs in the management of seizures in Namibia, specifically that of GPs. When one looks at the findings from this study, it becomes evident that GPs have little knowledge and experience in managing patients with MUS. This lack of knowledge and skill is most evident in the microsystem of the EST and impacts on the meso- and exosystems with the ineffectual rotation of patients between primary care HCPs, which is further complicated by the unaffordability of healthcare, lack of access to specialists and equipment and the indiscriminate use of AEDs. It is thus evident that PNES causes direct and indirect costs by placing a heavy burden on emergency and nonemergency healthcare services, and on the economy as a whole (Ahmedani et al., 2013; Asadi-Pooya & Emami, 2013; Martin et al., 1998). Unfortunately, a resource-poor country such as Namibia can ill afford this type of investment in a single disorder when faced with a plethora of other health conditions that require urgent attention. In the case of ES, where GPs expressed more confidence in being able to diagnose and treat the condition, patients regularly seem to seek second opinions from other HCPs and THPs, which in turn has financial and resource-utilization implications. This illustrates how an HCP action in the microsystem (diagnosis), affects a patient's decision in the mesosystem (to seek a second opinion) and finally results in frustrations in both the meso- and exosystems. This begs the question why patients still chose to explore alternatives even when a successful diagnosis of ES has been made. This tendency to explore alternatives for healing may be explained by patients' health-seeking behaviour patterns.

In Namibia, many patients with seizures may first seek treatment from a biomedical HCP. A diagnosis of an incurable but controllable disease is often deemed unacceptable and in

some cases prompt patients to seek treatment from a THP (Lebeau, 1999). According to the literature, health-seeking behaviour is a multifaceted process based on a combination of political, structural and social factors (Cooper, 2016). Furthermore, health-seeking behaviour in Africa is a multi-layered process grounded in a variegated range of healing styles and therapeutic preferences (Read, 2012; Read et al., 2009). For example, an anthropological study conducted in neighbouring Katutura found that a patient's view of the world determines what treatment modality is chosen, and this may differ substantially from a biomedical approach. In addition, a patient may use a variety treatment modalities either based on their perception of the problem or on whatever treatment is available (Waters Lumpkin, 1993). Viewed from the perspective of the EST, factors in the macrosystem, such as cultural attribution and SES influences perceptions in the microsystem (EM), which results in patients choosing a certain behaviour pattern in the mesosystem. In the PNES survey, HCPs indicated a lack of collaboration between HCPs and THPs as one of the challenges in providing adequate healthcare to seizure patients. It was therefore deemed essential to explore this response in more detail in the ES survey. Similar to a study conducted in Ghana, HCPs indicated their willingness to accommodate THPs in the treatment of seizures, albeit dependent on the successful regulation of THPs in Namibia (Ae-Ngibise et al., 2010). HCPs also acknowledged that increased training and education of GPs and other healthcare workers might improve epilepsy care (Wabila et al., 2017).

Possibly the biggest frustration and source of concern raised by both HCPs and THPs related to the absence of collaboration and agreement among the different disciplines. This was primarily noted in the mesosystem. For example, Bora et al. (2011) argue that there is a lack of cooperation in many epilepsy centres. This was illustrated by the fact that 91 per cent of PNES patients in their study were prescribed unnecessary AEDs as a result of neurologist intervention without the assistance of a psychiatrist. In addition, Kanner (2003) calls the lack of cooperation between neurologists and psychiatrists a *bizarre phenomenon* and professes that the future of PNES patients looks bleak as long as psychiatrists and neurologists function in isolation. This equates to the overall findings of this study where GPs and psychologists seldom succeed in maintaining a harmonious relationship, with a lack of communication at the root of the discontent.

Looking at the findings of this study, primary HCPs' management plans focused mainly on biological management and seldom included practitioners from other professions. So, unless primary care HCPs are prepared to entertain alternative explanations for some illness episodes to biomedical causes, and acknowledge that all illness episodes include a psychosocial component, a multidisciplinary approach to seizure management in Namibia is doomed to fail. This particular perception impacts on various levels of the EST, from actions in the microsystem that determine diagnosis and treatments, to patient reactions in the mesosystem, to the recognition of

THPs and secondary HCPs in the exosystem and finally to the acknowledgment of the role of culture in the macrosystem.

### **8.8. Contributions and Implications for Clinical Practice, Policy Making and Future Research**

By considering the findings of the entire study, it is possible to identify two main issues that seem to capture the essence of HCPs and THPs' perceptions and experiences in the management of seizures in Namibia. These two issues related to financial constraints and of lack of awareness and knowledge about seizures.

The survey results listed financial constraints as the most significant obstacle in accessing healthcare services. This was corroborated by information gained from interviews with HCPs and THPs. Seizure disorders are expensive conditions due to the costs involved in consulting various specialists and having to undergo multiple tests and investigations to arrive at a diagnosis. The same concern is evident from the literature, which states that to diagnose a person with PNES, considerable costs are incurred over an extended period for numerous procedures, tests and treatments (Reuber et al., 2002). In addition, financial constraints extended towards the shortage of specialized equipment and services in Namibia. By returning to the different systems of the EST that was used to interpret the findings of this study, one finds that financial concerns are mainly located in the meso- and exosystems of the model. However, the most salient theme throughout this study centred on the lack of awareness and knowledge regarding seizures and this theme permeated all the systems of the EST. It can therefore be postulated that by effecting change to a theme that repeats across all the systems in the model, one might be able to bring pervasive change to all the levels of the EST, including the financial constraints located in the meso- and exosystems. This particular barrier is less dependent on financial factors and underscores how the power of knowledge can shape perceptions and experiences.

Given the lack of resources in terms of skilled manpower, finances and healthcare facilities endemic to resource-poor countries, it is crucial that the available resources be applied in the most judicious and circumspect manner possible. However, Namibian stakeholders will be hard-pressed to advocate for the much-needed resources that can improve the lives of patients with seizures as long as there are no epidemiological data available to back up their claims. For instance, there is currently no statistical information available for PNES or ES in Namibia, although prevalence is estimated to be higher than currently reported in the literature. Given the unique demographics of the country, its developing nature and the reported lack of access to specialized services and equipment, it may be possible that the prevalence of seizures are underreported. It may therefore be worthwhile to establish the incidence and prevalence,

combined with the medical and social burden of the disorder to disseminate information for seizure incentives.

Towards this end, the availability of epidemiological data will not only increase the understanding of seizures in Namibia, but will also inform the planning and execution of healthcare interventions (Thurman et al., 2011). However, in order to ensure that a population-based epidemiological study yields data that are consistent and comparable between populations, the attributes of economy, acceptability, accuracy and representativeness have to be considered (Thurman et al., 2011). It is further evident from Thurman et al.'s (2011) article that an undertaking of such magnitude should not be underestimated and a significant amount of preparation precedes the planning and execution of a high validity epidemiological study. Taking into consideration some of the factors mentioned in the above standards document, it becomes obvious that much more research regarding seizures is needed in Namibia before a fully-fledged epidemiological study will become a reality.

The present study is but the first of its kind in Namibia and paves the way for future research on seizures in this developing, resource-poor country. By heeding the guidelines from the standards document and combining it with the findings of this exploratory study, one can identify some focus areas for future research. It is also important to utilize the findings from previous studies performed in similar contexts to guide the process of building a knowledge base that can be adapted to Namibian circumstances.

Future research will require the input of various data sources, which may include the public and private healthcare sectors, population surveys and patients (Thurman et al., 2011). This corresponds to suggestions that were made in some of the manuscripts that future research should include state healthcare workers, patients and the broader public to generate a more inclusive view of seizures in Namibia. Towards this end, the current study was able to point out that there are challenges in how seizures are managed in Namibia and that these challenges not only include HCPs and THPs, but also other role players. The study was also able to highlight that most of these challenges related to lack of knowledge and awareness about seizures and that future research should aim to address these. Participants asked for training opportunities for HCPs and THPs, awareness campaigns aimed at the public, and health literacy programmes for patients. All these depend on the successful identification of exactly what is required of these interventions in terms of a Namibian audience. This brings the discussion back to the need for more knowledge, which can only come from more research.

Specific topics mentioned by HCPs that require more exploration centred on difficulties experienced by HCPs in the diagnosis of PNES. Brown et al. (2011) recognize that HCPs, and specifically non-specialists, still find the differentiation of PNES from ES particularly challenging and conclude that this is a clear indication that more knowledge and skills are

needed to distinguish PNES in clinical practice. It was evident from the current findings that some HCPs, and especially GPs, may require more training to distinguish ES from PNES. A study that was part of an ILAE Commission on Neuropsychobiology Non-Epileptic Seizures Task Force initiative, reported that not all countries have access to vEEG, which is the gold standard for making a definitive PNES diagnosis (Benbadis, 2005; LaFrance Jr., Baker, et al., 2013). As an alternative, the authors outline a staged approach to diagnose PNES by evaluating key diagnostic methodologies that allow developing countries with lower and middle income population groups, such as Namibia, the opportunity to diagnose PNES in the absence of vEEG-monitoring (LaFrance Jr., Baker, et al., 2013). Guidelines such as these can aid in the training of GPs and other healthcare workers subject to its adaptation to Namibian conditions and the successful dissemination of the information to service providers.

In the same vein, participants indicated a need for standardized referral practices to facilitate transition of care among HCPs. Findings from the present study highlighted the challenges encountered in referring patients to other practitioners, something that often results in diagnostic delays and the ineffectual rotation of patients among various HCPs. Through the development of standardized methods for referral, it may be possible to decrease the time needed to diagnose and treat seizures, which may in turn result in a reduction of healthcare costs. The introduction of a multidisciplinary team that can ensure coordinated, high quality and patient-centred care may address these challenges, but a clearer understanding of the workings of such a team is required (Institute of Medicine, 2012). Future research is required to identify the possible role players that can contribute to such a team and the roles, responsibilities and communication structures necessary to make it a success.

This brings the discussion to THPs and the role that these providers play in the in the management of seizures. Early on in the study, a lack of communication between THPs and HCPs was mentioned as one of the key challenges in provision of care to patients. HCPs that participated in this study recognized that more collaboration with THPs is needed to account for the cultural attribution of seizures, but also that modern medical facilities alone cannot provide in the healthcare needs of people suffering from seizures. In an effort to understand the role of THPs in the management of seizures, Manuscript four set out to explore the experiences of traditional and faith healers and how seizures are customarily perceived and treated in non-western cultures. The results from this investigation provided some remarkable insights into THPs' ability to distinguish between seizures as a result of identifiable physical causes and seizures that originate as a result of psychological or spiritual causes. However, despite evidence that THPs play an integral role in the treatment of epilepsy in Africa, THPs' role in the treatment of seizures in Namibia remains unrecognized and their practices unregulated (Baskind & Birbeck, 2005b; Keikelame & Swartz, 2015; Kendall-Taylor et al., 2008; Njamnshi et al., 2010;

Stekelenburg et al., 2005). Until such time when THPs are formally recognized as legitimate service providers and their role in the treatment of seizures acknowledged, their contribution to healthcare will not be utilized to the fullest extent. This necessitates future research aimed at informing government policies regarding regulatory bodies that recognize the role of THPs in healthcare provision. Finally, the inclusion of the perspectives of THPs could contribute to later studies on how to achieve culturally inclusive healthcare services for patients with seizures.

At this point in the discussion, it is necessary to return to the importance of gathering the requisite information to realize the above goals for future research. This requires the input of various stakeholders in the seizure management chain and depends on the willingness of these sources to engage in the processes necessary to secure adequate data collection. To quote the guideline of “Acceptability” as described by Thurman et al. (2011, p. 4), “Data collection may require the acceptance and cooperation of many persons and organizations involved in reporting cases. Subjects may be asked to provide substantial time taking surveys and participating in other assessments.” One also has to take into account that there is a near absence of computerized database systems that can provide coded data on individual patients in Namibia. Therefore, before such a process can even be considered, it is imperative to increase awareness about seizures in the Namibian population. This will rely on the introduction of awareness campaigns that target stigmatization and negative attitudes towards PWE. It may also eradicate ignorance, improve seizure literacy and create acceptance and understanding about the impact of seizures on people’s lives (Sebera et al., 2015). Towards this end it is important to establish a common terminology for seizure-related illnesses to prevent misunderstanding and to make provision for cultural interpretations and differences in languages and concepts used to describe seizures (Thurman et al., 2011). By raising awareness, one might encourage the Namibian population to participate in future research about seizures. In addition, the knowledge that can be gauged from such research might strengthen one’s position to negotiate with the stakeholders responsible for policies and funds to address the current circumstances of seizure patients in Namibia.

Despite the methodological limitations, this study is the first of its kind to be conducted in Namibia and the findings may serve as a point of departure for future research on this topic. These findings have highlighted the perceptions, frustrations and the circumstances in which HCPs and THPs diagnose and treat seizures and make a valuable contribution to the existing knowledge about this disorder. Although access to specialized services and a lack of financial resources featured strongly among responses, lack of knowledge and awareness about seizure disorders play a major role in how these conditions are managed. Insufficient economic resources may limit the provision of services and are difficult to address, but campaigns aimed at increasing awareness may contribute significantly to alleviating the seizure burden.

This raises the question of responsibility and who should address and drive the initiatives discussed here. Whereas this discussion started with the delineation of roles insofar seizure management in Namibia is concerned, it is also evident that a shortage of primary HCPs may prevent these providers from becoming the driving force towards change. This presents an opportunity for secondary HCPs, such as psychologists and social workers, to become more proactive in addressing the challenges described in this study. The psychosocial impact of seizures cannot be denied and was highlighted throughout this dissertation. This combines with the fact that treatment for PNES is mostly found in psychotherapy (Krebs, 2007). Secondary HCPs are therefore well placed to take up the baton and address the needs identified in this study.

### **8.9. Researcher Reflections**

According to the literature, researcher reflexivity allows the researcher the opportunity to reflect on how personal experiences, subjective values, feelings, attitudes and worldviews may have affected the research process (Long & Johnson, 2000; Morrow, 2005). As a first-time researcher on the topic of seizures in Namibia and as part of the process to ensure that the findings reported in this dissertation are trustworthy, it is important to reflect on my experiences during the process of conducting the study.

As my own background may have influenced how I approached and conducted this study, the reflection process starts with a description of my personal values, feelings and attitudes. My motivation to embark on a project of this magnitude probably stemmed from being married to a PWE and witnessing the effect of this condition on both the person and the people around the person. My husband was diagnosed with ES approximately 12 years ago and I was involved in the process of diagnosis and treatment as his spouse. Although he had been seizure free for some years, he continues to take AEDs. However, those first experiences remained with me and acted as a source of motivation to make the world a better place for other people with seizure disorders.

Given my background as a systems analyst who gave up the world of computers for a world of psychology, my approach to this dissertation may reflect some of my previous training. I was once told that I am very “pragmatic” and that this may influence my ability to think outside “the box.” I have to acknowledge that this might be true, but I did endeavour to remain aware of this trait and to challenge myself to sometimes step outside the lines. What my previous training did give me was a clear idea of what I was trying to achieve, and the ability to retain this focus for the duration of the study. Working and studying in the field of psychology for the past 12 years as a white female, aged around the latter part of 40, definitely played a role in how I view the world. I do think that mature students are exposed to unique challenges, but it also brings with it a certain determination to succeed despite obstacles in the way. I would like to think that I

approached these obstacles with the necessary grace and consideration for the people that participated in this study. However, my more recent occupation as a psychological counsellor in private practice may have created some preconceived ideas about mental disorders and the role of HCPs, specifically psychiatrists and GPs, in treating such disorders. This research project required me to interact with other HCPs in the role of a researcher and not necessarily as a colleague. Given the fact that the healthcare community in Namibia is quite small, it was sometimes daunting to approach HCPs from other professions to participate in the study. While this familiarity sometimes proved helpful in recruiting participants for the study, it also necessitated that I remain objective in my interactions with the HCPs.

This proved to be challenging, yet constructive, as it made me aware of the challenges experienced by other mental healthcare professionals in providing services in an environment where such services are not necessarily valued or understood. Moreover, I found that GPs and neurologists welcomed the opportunity to contribute to the research and seemed genuinely interested in what I was doing. I feel that I have gained a better understanding of the context in which HCPs operate and I could challenge some of my preconceived ideas regarding the provision of services to patients. To minimize the impact of researcher bias, I compiled a detailed profile for each HCP (see Appendix G) in which I reflected on the interviewing process by noting my impressions and some of the reactions observed in the HCPs.

Insofar as the interaction with THPs is concerned, this was truly a novel experience. Coming from a background of Western beliefs and culture, it proved challenging and daunting for this mature, white woman to gain entry into the world of traditional medicine. The healers and I did not share the same cultural heritage or ethnic origins and this contributed to the novelty of the experience. However, once an opening presented itself, the process unfolded in many surprising ways. It was both educational and inspirational to experience the world of traditional healing. In some aspects, my lack of exposure to this culture served me well, as I did not have many preconceived ideas and was able to enter this world with an open mind. Although there may have been a certain amount of bias towards traditional practices, coming from a biomedical background, this was soon dispelled. Detailed profiles of my encounters with the THPs was compiled to maintain a full history of the interview process and to give me an opportunity to reflect on these experiences (see Appendix G).

An overriding emotion during the execution of this study relates to the feeling that participants harboured certain expectations regarding the outcome of this research. This sometimes created a feeling of pressure to deliver a product that will make an immediate difference to the current situation in Namibia. However, I had to place these expectations in context and instead focus on seeing this dissertation as the first step in a process that can improve

the lives of not only people with seizures, but also of those involved in providing healthcare to this population.

### **8.10. Concluding remarks**

This dissertation set out to investigate the perceptions and experiences of HCPs and THPs in the management of seizures. It achieved its goal and much was learned about the conceptualization, diagnosis and treatment of ES and PNES in Namibia. However, much still remains to be learned before a substantive difference can be made in how this debilitating condition affects the lives of millions of people in Africa. This research is but a first step in bringing about change for seizure patients in a developing, resource-poor country. These two terms, “developing” and “resource-poor” were frequently used throughout this study to illuminate the study conditions. It was used to explain why there is a lack of expertise and equipment and healthcare and formed the basis for many of the challenges experienced by HCPs and THPs when faced with seizures disorders. What it does not explain is the willingness and the eagerness of the people to “develop.” Therein lies the strength of this country. The reactions, support and the expectations of the participants showed that this is not an entirely “resource-poor” country. This is a “hungry” country. There is a hunger for change, for more information, education, training, for more opportunity. This research affords just such an opportunity. Given the resources that Namibia has in terms of its people and their preparedness to engage and become part of the solution, a study of this nature might just make a difference.

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**INTRODUCTION**

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WHO Permissions team

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ID: 233710

Section: Contact details

-----

\* Title

\* Mrs

-----

\* First name

\* Anina

-----

\* Family name

\* du Toit

-----

\* Organization/affiliation

\* Stellenbosch University

-----

\* Web site address

\*

-----

\* Type of organization

\* University/Academic

-----

\* If other, please specify

\*

-----

\* If STM signatory, please select

-----

\* Position

\*

\* Telephone

\* +264811490010

\* Address

\* Stellenbosch University, Department of Psychology, Wilcocks Building, Victoria Street,  
Stellenbosch 7130, South Africa

\* Country

\* South Africa

\* Email

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\* Meyer, Ana-Claire, et al. "Global disparities in the epilepsy treatment gap: a systematic review." *Bulletin of the World Health Organization* 88.4 (2010): 260-266.

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\* <http://www.who.int/bulletin/volumes/88/4/09-064147/en/>

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\* Fig. 4. Mean epilepsy treatment gap (%) and standard errors by rural/urban status, World Bank income category and year data collected

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\* Seizures: The Perceptions and Frustrations of Healthcare Providers and Traditional Health Practitioners in Namibia

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\* Print, PDF

## Appendix B1: Informed Consent for HCP re PNES



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### STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

---

## **PNES: NAMIBIAN HEALTHCARE PROVIDERS' PERCEPTIONS AND FRUSTRATIONS**

REFERENCE NUMBER: REC-050411-032

PRINCIPAL INVESTIGATOR: Anina du Toit (BA Hons Psychology)

ADDRESS: 10 Barella Street, Klein Windhoek, Windhoek, Namibia, 9000

CONTACT NUMBER: 081 149 0010

You are asked to participate in a research study conducted by Anina du Toit, from the Psychology Department at Stellenbosch University. Results from this study will be contributed to thesis research. You were selected as a possible participant in this study because you have been identified as a healthcare provider specialising in rendering services to patients suffering from epilepsy and/or psychogenic nonepileptic seizures (PNES).

Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **1. PURPOSE OF THE STUDY**

This study aims to explore the perceptions and frustrations experienced by healthcare providers in diagnosing and treating patients suffering from PNES. For the purpose of this study, a healthcare provider has been defined as an individual who is responsible for the diagnosing, treating and/or rendering of services to patients suffering from PNES.

### **2. PROCEDURES**

If you volunteer to participate in this study, we would ask you to do the following things:

- Complete an anonymous survey consisting of 35 questions.

- Some participants will be invited to partake in a once-off semi-structured interview that will last approximately 20-30 minutes, during which you will talk about the perceptions and frustrations experienced in the course of diagnosing and treating patients suffering from PNES.

The study will be conducted at a time and place that suits you. Approximately 50 individuals will participate in this study. Data collection will be in the form of an online survey or electronic survey. Provision will be made for surveys to be completed in hard copy format. Semi-structured interviews will be conducted with 10-15 selected participants. Interviews will commence with the completion of a biographical questionnaire. This will be followed by a semi-structured interview, consisting of questions that relate to your perceptions and frustrations as a healthcare provider rendering services to patients suffering from PNES. The interviews will be conducted one-on-one, and I (a Psychology Masters student) will be conducting the interviews. Each interview will be approximately 20-30 minutes long. With your permission, the interview will be audio-recorded so that it can be transcribed verbatim for the data analysis. The participant retains the right to review/edit all recordings.

### **3. POTENTIAL RISKS AND DISCOMFORTS**

The proposed study can be classified as low risk as the research will be conducted on a largely uncontroversial topic through a survey and semi-structured interviews. The participants are adults (health-care professionals) and not considered to be a vulnerable research population. The research will compose of information that can be regarded as non-sensitive, such as opinion rather than personal information and will be collected anonymously through a mail survey and semi-structured interviews.

### **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Most of the studies that have been conducted on PNES have taken place in developed countries while developing countries such as Namibia have received less focus. A study of this nature has not been conducted in Namibia, and it is possible that the knowledge obtained from this study could be used to offer suggestions on how healthcare providers could manage the challenges they face in diagnosing and treating PNES patients.

There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Namibia, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the perceptions and frustrations experienced by healthcare providers in rendering services to patients suffering from PNES.

### **5. PAYMENT FOR PARTICIPATION**

You will not be paid to participate in this study; participation is wholly voluntary, and no reimbursement will be forthcoming.

### **6. CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning a code instead of using the participant's name. Participants will have the right to review/edit audio recordings of interviews. Only the researcher and her promoter will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the researcher's office, and it will be appropriately destroyed and discarded once the study is completed.

No confidential or identifying information will be used in the event that results from the study is published. Results from the study will be used to generate descriptive statistics only.

## 7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, although it is not anticipated that any circumstances can arise that would warrant such withdrawal.

## 8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact the Principal Investigator: Anina du Toit on 081 149 0010 or Promoter: Dr Chrisma Pretorius on +27 21 808 3435.

## 9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

<b>SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE</b>
--

By signing below, I, \_\_\_\_\_ agree to take part in a research study entitled PNEs: Namibian Healthcare Providers' Perceptions and Frustrations.

I declare that:

- I have read or had read to me this information and consent form, and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions, and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2015.

\_\_\_\_\_  
**Signature of participant**

\_\_\_\_\_  
**Signature of witness**

<b>SIGNATURE OF INVESTIGATOR</b>
----------------------------------

I (*name*) \_\_\_\_\_ declare that:

- I explained the information in this document to \_\_\_\_\_
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2015.

\_\_\_\_\_  
**Signature of investigator**

\_\_\_\_\_  
**Signature of witness**

**Appendix B2: Biographical Questionnaire for HCP**

Biographical information

Instructions: Please fill in your biographical information. Indicate your choices by circling the correct option.

Age: .....

Gender: Male/ Female

Ethnicity: African/Coloured/White/Other\*

If other, please specify:

.....

Marital Status:

.....

Home language:

.....

Email address:

.....

Contact number:

.....

Your qualifications:

.....

Do you specialize in any field?

.....

How long have you been a healthcare provider?

.....

**Appendix B3: Semi-Structured Interview Questions for HCP re PNES**

1. Tell me about your work with PNES patients.
2. How easy is it to diagnose PNES?
  - Tell me about your confidence to diagnose PNES
3. What are the complexities involved in making a diagnosis?
  - Access to tests such as EEG, vEEG etc.?
  - How is the diagnosis communicated to the patient?
4. Do you think there is a stigma attached to being diagnosed with PNES?
  - In that people fake it?
5. What are the general attitudes/reactions when people are diagnosed with PNES?
  - What do you generally tell patients with a diagnosis of PNES?
6. Do patients understand/accept the diagnosis?
7. What are in your experience the main causes of PNES?
8. What role does secondary gain play in the diagnosis?
  - Do patients want to benefit from disability benefits?
9. What is your opinion regarding referral of patients?
  - What are the challenges in referring?
  - Are patients prepared to go to a mental health professional?
10. What would you consider to be the most effective treatment for PNES?
  - Availability of this in Namibia?
11. What are in your opinion the main challenges that health-care professionals face when dealing with patients with PNES?
12. What makes it easier (or will make it easier) for you as a health-care professional to deal with patients with PNES?
13. What is in your opinion the main challenges faced by patients with PNES?
14. What do you think makes it easier (or will make it easier) for patients with PNES?
15. Any final thoughts on the matter?

## **Appendix B4: Letter of Invitation to HCP for PNES**

### **PNES Treatment Survey**

#### **Current Practice in Diagnosis and Referral of Patients with Psychogenic Non-epileptic Seizures**

Dear Healthcare Provider,

Psychogenic Non-epileptic Seizures (PNES, also known as Dissociative or Conversion Seizures) are one of the most common differential diagnoses of epilepsy. A number of evidence-based treatments for PNES now exist.

The International League against Epilepsy (ILAE) has encouraged its Psychogenic Non-epileptic Seizure (PNES) Task Force to find out more about what diagnostic and treatment services are available for patients with PNES around the world. In order to address this question, the PNES Task Force has devised a simple questionnaire, which should only take ten to fifteen minutes to complete. You are invited to complete this 36-item survey because you have been identified as a service provider specializing in the treatment of epilepsy and PNES. Your participation is greatly valued, as this information will not only inform the diagnostic and treatment services (as well as service gaps) in Namibia, but we also intend to compare responses from Namibia with responses from other countries. The findings of both analyses may provide a basis for negotiations about investment in service improvements in your area, which should ultimately help you and your patients.

**EVEN IF YOU DO NOT DIRECTLY TREAT PATIENTS WITH PNES**, please complete this survey.

The link to the survey is: <https://www.surveymonkey.com/s/PNES>

Participation in the study is voluntary and anonymously. All responses will be kept confidential. By responding to this survey you will be indicating your consent to participate in this study. If you decide to participate, you are free to stop at any time and to choose not to answer specific questions.

If you have any questions about this study, please contact Anina du Toit, (081 149 0010) or via e-mail ([anina@letstalkpsych.biz](mailto:anina@letstalkpsych.biz)).

Thank you in advance for your participation.

Sincerely,

Anina du Toit (Hons)  
Masters Student, University of Stellenbosch

**Appendix B5: PNES Survey for HCP**

ILAE PNES Task Force - PNES Survey for Health Professionals

## INFORMED CONSENT

**PRINCIPAL INVESTIGATOR: Anina du Toit (BA Hons Psychology)****REFERENCE NUMBER: REC-050411-032****ADDRESS: 10 Barella Street, Klein Windhoek, Windhoek, Namibia, 9000 CONTACT NUMBER: 081 149 0010**

You are asked to participate in a research study conducted by Anina du Toit, from the Psychology Department at Stellenbosch University. Results from this study will be contributed to thesis research. You were selected as a possible participant in this study because you have been identified as a healthcare provider specializing in rendering services to patients suffering from epilepsy and/or psychogenic non-epileptic seizures (PNES).

1. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. **PURPOSE OF THE STUDY:** This study aims to explore the perceptions and frustrations experienced by healthcare providers in diagnosing and treating patients suffering from PNES. For the purpose of this study, a healthcare provider has been defined as an individual who is responsible for the diagnosing, treating and/or rendering of services to patients suffering from PNES. **PROCEDURES:** If you volunteer to participate in this study, we would ask you to do the following things: Complete an anonymous survey consisting of 35 questions. Approximately 50 individuals will participate in this study. Data collection will be in the form of an online survey or electronic survey. Provision will be made for surveys to be completed in hardcopy format. **POTENTIAL RISKS AND DISCOMFORTS:** The proposed study can be classified as low risk as the research will be conducted on a largely uncontroversial topic through a survey and semi-structured interviews. The participants are adults (health care professionals) and not considered to be a vulnerable research population. The research will compose of information that can be regarded as non-sensitive, such as opinion rather than personal information and will be collected anonymously through a mail survey and semi-structured interviews. **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY:** Most of the studies that have been conducted on PNES have taken place in developed countries, while developing countries such as Namibia have received less focus. A study of this nature has not been conducted in Namibia, and it is possible that the knowledge obtained from this study could be used to offer suggestions on how healthcare providers could manage the challenges they face in diagnosing and treating PNES patients. There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Namibia, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the perceptions and frustrations experienced by healthcare providers in rendering services to patients suffering from PNES.

Please tick YES if you understand and agree with the above-mentioned.

Yes

No

2. PAYMENT FOR PARTICIPATION: You will not be paid to participate in this study; participation is wholly voluntary and no reimbursement will be forthcoming. CONFIDENTIALITY: Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning a code instead of using the participant's name. Participants will have the right to review/edit audio recordings of interviews. Only the researcher and her supervisor will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the researcher's office and it will be appropriately destroyed and discarded once the study is completed. No confidential or identifying information will be used in the event that results from the study is published. Results from the study will be used to generate descriptive statistics only. PARTICIPATION AND WITHDRAWAL: You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, although it is not anticipated that any circumstances can arise that would warrant such withdrawal. IDENTIFICATION OF INVESTIGATORS: If you have any questions or concerns about the research, please feel free to contact the Principal Investigator: Anina du Toit on 081 149 0010 or Supervisor: Dr. Chrisma Pretorius on +27 21 808 3435. RIGHTS OF RESEARCH SUBJECTS: You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouché@sun.ac.za; 021 808 4822] at the Division for Research Development.

Please tick YES if you understand and agree with the above-mentioned.

YES

NO

ILAE PNES Task Force - PNES Survey for Health Professionals

A: About yourself

3. What is your age?

4. What is your gender?

Female

Male

5. Where do you practice, town?

6. Which kind of patients do you see? Tick all boxes that apply.

I work with hospital inpatients

I work with hospital outpatients

My work is community-based (outside hospital)

I see private patients (self-funding/medical aid)

I see state patients

Other (please specify)

7. Roughly what is the percentage of state patients you see? Not PSEMAS (0-100%)

8. Roughly what is the percentage of private patients (self-funding/medical aid/psemas) you see?

9. What patient groups do you see? Tick all boxes that apply.

- Children (aged 0-18)
- Adults (19-74)
- Elderly patients (75 and older)
- Male patients
- Female patients
- Patients with intellectual disability

10. What is your speciality? Tick all boxes that apply.

- Neurologist with special interest in epilepsy / Epileptologist
- General Neurologist
- Neuropsychology
- Neuropsychiatry
- Psychiatry
- Psychology
- Psychotherapy
- General/Internal Medicine
- General Practice
- Social Work
- Traditional Healer
- Clinical Officer in General Medicine
- Clinical Officer in Psychiatry
- Nurse Mental Health
- Epilepsy nursing
- General Nursing
- Counselling

Other (please specify)

11. What is your level of training in your health profession? Please select best answer.

- Fully trained
- In training

12. On average, roughly how many hours do most of your patients travel to see you? Please select best answer.

- Up to 1 hour
- 1 - 2 hours
- 3 - 4 hours
- 5 - 6 hours
- 7 - 8 hours
- 9 - 10 hours
- 10 -11 hours
- 12 - 24 hours
- > 24 hours

13. Tell us about your work with patients with PNES. (Please tick all boxes which apply)

- I refer patients to others for diagnosis when I suspect PNES.
- I personally diagnose PNES.
- I communicate the diagnosis of PNES.
- I refer patients with PNES to others once I have made the diagnosis and explained it to the patient.
- I recommended treatments for PNES.
- I arrange treatments for PNES.
- I provide psychological treatment for PNES (beyond explaining the diagnosis).
- I provide psychiatric treatment for patients with PNES.
- I prescribe medicines for patients with PNES.
- I provide follow-up for patients with PNES.

14. Please give an estimate of the number of patients with PNES who you diagnose per year? (Please select best answer)

- 0
- 1-5
- 6-10
- 11-20
- >20

15. Please give an estimate of the number of patients with PNES under your current care? (Please select best answer)

- 0
- 1-5
- 6-10
- 11-20
- 20-50
- >50

16. Which of the following options best describes your level of confidence about diagnosing PNES? (Please select one option)

- I do not really know how to distinguish between PNES and epilepsy.
- I am aware of the differences in appearance of epileptic seizures and PNES but I am uncertain about the diagnosis and do not know how to explain it to patients.
- I have seen epileptic seizures and PNES in real life, on video or in video-EEG recordings, am familiar with the typical appearance of PNES and make the diagnosis occasionally.
- I have seen epileptic seizures and PNES in real life, on video or in video-EEG recordings, am familiar with the typical appearance of PNES and make the diagnosis often.

17. Which of the following options best describes your level of confidence about treating PNES? (Please select one option)

- I do not know how to explain PNES or how to treat this disorder.
- I know how to explain the diagnosis of PNES but do not know how to treat this disorder.
- I know how to explain the diagnosis of PNES and what the treatment options are but I am not experienced with arranging or offering treatment.
- I am very familiar with PNES and how to explain the diagnosis, propose treatment options and arrange treatment.
- I am very familiar with PNES and provide treatment for the disorder.

18. As how familiar with psychotherapy would you describe yourself? (Please select one option)

- I do not know anything about psychotherapy or how it might work for PNES.
- I know about psychotherapy in theory but could not describe what it involved and how it might work.
- I know about psychotherapy, can describe the process in principle but not specifically in relation to PNES.
- I am well informed about a range of psychotherapeutic approaches and can describe how different approaches could help patients with PNES.

## ILAE PNES Task Force - PNES Survey for Health Professionals

## B: About PNES in your area

19. What do you estimate is the gender distribution of your patients with PNES? (Please select best answer)

- I have only seen PNES in women.
- I have seen PNES more often in women than in men.
- I have seen PNES in as many women as in men.
- I have seen PNES more often in men than in women.
- I have only seen PNES in men.



## ILAE PNES Task Force - PNES Survey for Health Professionals

## C: About your diagnostic service for patients with PNES

21. Which diagnostic tests do you have access to? (Please select all that apply)

- Routine EEG (30 minutes recording)
- Routine EEG with video (30 minute recording)
- Prolonged outpatient EEG without video (1-8 hour recording)
- Prolonged outpatient EEG with video (1-8 hour recording)
- Outpatient ambulatory EEG
- Inpatient video-EEG (longer than 8 hours)
- Video-EEG in patients' homes
- Neuropsychological testing
- Postictal prolactin measurement
- Computed tomography of the head
- Magnetic resonance imaging of the head
- Tilt-table examination
- Routine heart recording (EEG/EKG, less than 5 minutes)
- 24 hour ambulatory heart recording
- 24 hour ambulatory blood pressure recording
- Long-term heart rhythm monitoring with implantable device





## ILAE PNES Task Force - PNES Survey for Health Professionals

## D: About your management of PNES

25. Who typically first communicates the diagnosis of PNES to your patients? (Please select one answer)

- Neurologist
- Nurse
- Family doctor
- Psychologist
- Neuropsychologist
- Counsellor/ Therapist
- Psychiatrist
- Neuropsychiatric
- Clinical Officer General Medicine
- Clinical Officer Psychiatry
- Medical Officer (Government hospital)

26. How is the diagnosis of PNES usually communicated to the patient? Please select all that apply.

- Letter to the patient
- Face to face explanation to the patient
- Face to face explanation to the patient's family if present
- Letter to another healthcare practitioner
- Leaflet about PNES for patient/family
- Patient referral to websites about PNES
- Patient referral to self-help groups
- Diagnosis of PNES is not explicitly communicated

27. Which of the following statements would you typically include in your discussion of PNES? (Please select all that apply)

- I do not discuss the diagnosis of PNES with patients.
- I say that the events are medically unexplained.
- I do not offer a detailed psychological explanation.
- I say that the events are a response to stress.
- I say that the events may be a sign of suppressed traumas from the past or ongoing conflicts.
- I say that PNES are often the result of trauma.
- I say that PNES are often the result of sexual abuse.
- I say that the cause of PNES are complicated and that there may be predisposing factors, factors which first started attacks and factors which maintain the problem.
- I say that the events are a form of epilepsy which does not need drug treatment.
- I say that the events are not a form of fits or epilepsy and do not cause any lasting damage.
- I say that the events are not a form of possession by evil spirits and that it is a medical or psychiatric condition.
- I say that the person is not deliberately producing those events.
- I say that the person is not aware of PNES.
- I say that PNES are a mental health problem.
- I say that antiepileptic drugs do not work for PNES.
- I say PNES are a form of seizures which can improve with psychotherapy.

28. Which of the following reasons would lead you to continue following patients up after the communication of the diagnosis? (Please select all that apply)

- I do not follow patients with PNES up once I have made the diagnosis
- I follow up patients who continue to doubt the diagnosis.
- I follow up patients with PNES and additional epilepsy.
- I follow up patients with PNES and additional mental health problems.
- I follow up patients with PNES reducing antiepileptic drugs.
- I follow up patients with PNES whose seizures have stopped but could return.
- I follow up patients who have not yet engaged with a psychiatric / neuropsychiatric service.
- I follow up patients who have not yet engaged in psychotherapy.
- I follow up patients with PNES for whom I have prescribed medication.
- As a rule I offer all patients with PNES at least one follow up appointment after I have explained the diagnosis.

29. What is your best estimate of the percentage of patients with PNES who you invite to come back to you for at least one follow-up visit after the diagnosis has been communicated to them (0-100%)

30. Which of the following treatment options would you consider the most effective treatment for PNES? (Please select one option)

- Individual psychological treatment (Cognitive Behavioural Therapy or other forms of psychological treatment)
- Group psychotherapy
- Antidepressant drugs
- Antipsychotic drugs
- Anti-epileptic drugs
- Beta-blockers
- Benzodiazepines
- Religious ceremonies including exorcism of evil spirits
- Placebo drug treatment
- Herbal mixtures
- Homeopathic preparations
- Hypnosis
- Acupuncture
- I do not think any treatment is effective
- Other (please specify)

31. Roughly what proportion of your patients with a diagnosis of PNES would in reality have access to the following treatments (taking into account the costs of the test, patients' ability to pay or health insurance coverage, travel from home to the site of the healthcare provision, and similar major obstacles but excluding patient's possible reluctance to undergo tests):  
 (Please provide estimates of all listed treatments - use 0% if you do not think a factor is relevant)

	0%	1-10%	11-20%	21-30%	31-40%	41-50%	51-60%	61-70%	71-80%	81-90%	91-100%
Education (telling the patients +/- their family about the diagnosis of PNES)	<input type="radio"/>										
Support groups	<input type="radio"/>										
Individual outpatient psychological treatment (Cognitive behavioural Therapy or other forms of psychological treatment)	<input type="radio"/>										
Outpatient psychological group treatment	<input type="radio"/>										
Outpatient psychological family treatment	<input type="radio"/>										
Inpatient treatment (e.g including psychotherapy, rehabilitation)	<input type="radio"/>										
Antidepressant drugs	<input type="radio"/>										
Antipsychotic drugs	<input type="radio"/>										
Anti-epileptic drugs	<input type="radio"/>										
Beta-blockers	<input type="radio"/>										
Benzodiazepines	<input type="radio"/>										
Occupational therapy	<input type="radio"/>										

32. Is psychotherapy (Cognitive Behavioural Therapy or other forms of psychological treatment) available in my area? (Please tick all that apply)

No psychotherapy is available in my area

Psychotherapy is available for private patients

Psychotherapy is available for publicly insured patients

Psychotherapy is available via telemedicine / tele health / internet-based services

Other (please specify)

33. What is your best estimate of the proportion of your patients with PNES who will be offered at least one appointment for psychological treatment (including those who will fail to attend)  
(Please select one option)

- 0%
- 10%
- 20%
- 30%
- 40%
- 50%
- 60%
- 70%
- 80%
- 90%
- 100%

34. If psychological treatment is offered in your area, what is the typical waiting period from the time of referral to the first appointment in months? (For two weeks use 0.5) \_\_\_\_ months / not applicable (no psychotherapy is available)

## ILAE PNES Task Force - PNES Survey for Health Professionals

## E: About the health service you work in

35. How is the care you provide for patients with PNES paid for? (Please estimate the proportion of the diagnostic / treatment costs related to PNES which is reimbursed using the following payment methods - use 0% if a payment method is not used. If you see public and private patients, please answer this question thinking of the type of patient you most commonly see - private or public)

	0%	1-10%	11-20%	21-30%	31-40%	41-50%	51-60%	61-70%	71-80%	81-90%	91-100%
Out-of-pocket / self-pay	<input type="radio"/>										
Social Insurance / government (state) health care	<input type="radio"/>										
Private Medical Aid / Insurance	<input type="radio"/>										
Private Foundation	<input type="radio"/>										
Free medical aid	<input type="radio"/>										

36. May patients you see receive state disability benefits because of their PNES?

- Yes
- No

37. Please estimate the proportion of your patients who have difficulties with accessing your diagnostic or treatment services for PNES for the following reasons.  
 (Please provide estimates of all listed factors - use 0% if you do not think a factor is relevant)

	0%	1-10%	11-20%	21-30%	31-40%	41-50%	51-60%	61-70%	71-80%	81-90%	91-100%
Illiteracy	<input type="radio"/>										
Language / communication difficulties with healthcare professionals	<input type="radio"/>										
problems with travel / geographic access to healthcare provider	<input type="radio"/>										
Lack of money for tests	<input type="radio"/>										
Lack of money for appointments with non-specialist healthcare professional	<input type="radio"/>										
Lack of money for appointment with seizure expert	<input type="radio"/>										
Lack of accessible healthcare practitioners who know about PNES	<input type="radio"/>										
Lack of psychological treatment services	<input type="radio"/>										
Lack of money for psychotherapy	<input type="radio"/>										
Lack of money for drug treatment	<input type="radio"/>										
Stigma associated with PNES	<input type="radio"/>										
Lack of referral system to seizure experts	<input type="radio"/>										
Lack of liaison between traditional healers and health professionals	<input type="radio"/>										
Lack of popular awareness of PNES	<input type="radio"/>										
Lack of access to information resources about PNES (such as leaflets / internet)	<input type="radio"/>										
Lack of intellectual capacity (for instance because of intellectual disability)	<input type="radio"/>										
Other (please specify)	<input type="text"/>										

38. Please add any comments you believe are relevant but have not been asked.

**Appendix C1: Letter of Invitation to HCP for ES**

## Epilepsy Treatment Survey

## Current Practice in Diagnosis and Referral of Patients with Epileptic Seizures

Dear Healthcare Provider,

Epilepsy affects 65 million people worldwide and approximately 80% of those live in low- and middle income countries (Moshé, Perucca, Ryvlin, & Tomson, 2015). However, there are currently no formal statistics on prevalence, incidence or diagnostic and treatment procedures available for epilepsy in Namibia (Angula, 2016). Epilepsy is the most common, chronic and serious neurological disease worldwide and involves a major burden in terms of costs, mortality, stigma, seizure-related disability and comorbidities (Moshé et al., 2015).

As part of my PhD study, *Seizures: The Perceptions and Experiences of Healthcare Providers and Traditional Health Practitioners in Namibia*, I am investigating what diagnostic and treatment services are available for patients with ES in Namibia. In order to address this question, I devised a simple questionnaire which should only take ten to fifteen minutes to complete. You are invited to complete this 26 item survey because you have been identified as a service provider specializing in the treatment of seizures and epilepsy. Your participation is greatly valued, as this information will not only inform the diagnostic and treatment services (as well as service gaps) in Namibia, but we also intend to compare responses from Namibia with responses from other countries. The findings of both analyses may provide a basis for negotiations about investment in service improvements in your area, which should ultimately help you and your patients.

EVEN IF YOU DO NOT DIRECTLY TREAT PATIENTS WITH SEIZURES, please complete this survey.

The link to the survey is: <https://www.surveymonkey.com/r/NH8VBMT>

Participation in the study is voluntary and anonymous. All responses will be kept confidential. By responding to this survey you will be indicating your consent to participate in this study. If you decide to participate, you are free to stop at any time and to choose not to answer specific questions.

If you have any questions about this study, please contact Anina du Toit, (081 149 0010) or via e-mail ([anina@letstalkpsych.biz](mailto:anina@letstalkpsych.biz)).

Thank you in advance for your participation.

Sincerely,

Anina du Toit (Hons)

PhD Student, University of Stellenbosch

**Appendix C2: Informed Consent for HCP re Seizures**

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STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

SEIZURES: THE PERCEPTIONS AND FRUSTRATIONS OF HEALTHCARE PROVIDERS AND  
TRADITIONAL HEALTH PRACTITIONERS IN NAMIBIA

NHREC REGISTRATION NUMBER: REC-050411-032

PRINCIPAL INVESTIGATOR: Anina du Toit (BA Hons Psychology)

ADDRESS: 10 Barella Street, Klein Windhoek, Windhoek, Namibia, 9000

CONTACT NUMBER: 081 149 0010

You are asked to participate in a research study conducted by Anina du Toit, a PhD student from the Psychology Department at Stellenbosch University. Results from this study will be contributed to dissertation research. You were selected as a possible participant in this study because you have been identified as a healthcare provider specializing in rendering services to patients suffering from seizures.

Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Research Ethics Committee: Human Research at Stellenbosch University (Humanities)** and will be conducted according to the ethical guidelines and principles of the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

**PURPOSE OF THE STUDY**

This study aims to explore the perceptions and experiences of healthcare providers and traditional health practitioners in diagnosing and treating patients who experience seizures. For the

purpose of this study, a healthcare provider is defined as an individual who is responsible for the diagnosing, treating and/or rendering of services to patients who experience seizures. A traditional healthcare practitioner is defined as an individual who treats or renders traditional healthcare practices to a person who experiences seizures. This study can contribute significantly to the knowledge gap between traditional and conventional healthcare provision in an attempt to improve quality of care to seizure patients in Namibia. Second, this study could potentially contribute to a more collaborative relationship between HCPs and THPs in this country. Third, the proposed multi-layered investigation could also inform government policies regarding the provision of adequate healthcare infrastructure and regulatory bodies that recognize the role of THPs in healthcare provision. Finally, the inclusion of the perspectives of THP's could contribute significantly to the rendering of culturally inclusive healthcare services for seizure patients in order to effectively manage this condition.

## PROCEDURES

If you volunteer to participate in this study, you would be asked to do one or both of the following things depending on your own preference:

- Complete an anonymous survey consisting of 27 questions.
- Some participants will be invited to partake in a once-off semi-structured interview that will last approximately 20-45 minutes, during which you will talk about your perceptions and experiences in the course of diagnosing and treating patients suffering from epilepsy and/or seizures.

The study will be conducted at a time and place that suits you. Approximately 50 individuals will participate in this study. Semi-structured interviews will be conducted with 15-25 selected participants. Interviews will commence with the completion of a biographical questionnaire. This will be followed by a semi-structured interview, consisting of questions that relate to your perceptions and experiences as a healthcare provider rendering services to patients suffering from epilepsy and/or seizures. The interviews will be conducted one-on-one and I (a Psychology PhD student) will be conducting the interviews. Each interview will be approximately 20-45 minutes long. With your permission, the interview will be audio-recorded so that it can be transcribed verbatim for the data analysis. The participant retains the right to review/edit all recordings.

## POTENTIAL RISKS AND DISCOMFORTS

The proposed study can be classified as low risk as the research will be conducted on a largely uncontroversial topic through a survey and semi-structured interviews. As an HCP you are an adult and not considered a vulnerable research population. The research will compose of information that can be regarded as non-sensitive, such as your opinion rather than your personal information and will be collected anonymously through a mail survey and semi-structured interviews.

## POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Most of the studies that have been conducted on seizures have taken place in developed countries, while developing countries such as Namibia have received less focus. A study of this nature has not been conducted in Namibia, and it is possible that the knowledge obtained from this study could be used to offer suggestions on how healthcare providers could manage the challenges they face in diagnosing and treating seizure patients.

There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Namibia, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the perceptions and experiences of healthcare providers in rendering services to patients suffering from seizures.

## PAYMENT FOR PARTICIPATION

You will not be paid to participate in this study; participation is wholly voluntary and no reimbursement will be forthcoming.

## CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning a code instead of using the participant's name. Participants will have the right to review/edit audio recordings of interviews. Only the researcher and her supervisor will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the researcher's office and it will be appropriately destroyed and discarded once the study is completed.

No confidential or identifying information will be used in the event that results from the study are published. Results from the study will be used to generate descriptive statistics only.

## PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, although it is not anticipated that any circumstances can arise that would warrant such withdrawal.

## IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact the Principal Investigator: Anina du Toit on 081 149 0010 or Supervisor: Dr Chrisma Pretorius on +27

21 808 3435.

#### RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

<b>SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE</b>
--

By signing below, I, \_\_\_\_\_ agree to take part in a research study entitled Seizures: Perceptions and Experiences of Namibian Healthcare Providers and Traditional Health Practitioners in Namibia.

I declare that:

- The information above was described to me in a language that I understand.
- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I have been given a copy of this form.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2017.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Signature of witness

**SIGNATURE OF INVESTIGATOR**

I (*name*) \_\_\_\_\_ declare that:

- I explained the information in this document to \_\_\_\_\_
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2017.

\_\_\_\_\_  
Signature of investigator

\_\_\_\_\_  
Signature of witness

**Appendix C3: Semi-Structured Interview Questions for HCP re ES**

1. Tell me about your work with seizure patients.
2. How easy is it to diagnose epileptic seizures?
  - Tell me about your confidence to diagnose epilepsy
3. What are the complexities involved in making a diagnosis?
  - Access to tests such as EEG, VEEG etc.?
  - How is the diagnosis communicated to the patient?
4. Do you think there is a stigma attached to being diagnosed with epilepsy?
5. What are the general attitudes/reactions when people are diagnosed with epilepsy?
  - What do you generally tell patients with a diagnosis of epilepsy?
6. Do patients understand/accept the diagnosis?
7. What are in your experience the main causes of epilepsy?
8. What role does secondary gain play in the diagnosis?
  - Do patients want to benefit from disability benefits?
9. What is your opinion regarding referral of patients?
  - What are the challenges in referring?
  - Are patients prepared to go to a mental health professional?
10. What would you consider to be the most effective treatment for epilepsy?
  - Availability of this in Namibia?
11. Do you think that Traditional Healers can play a role in the treatment of seizures?
  - Do you refer to THPs? Or get referrals from THPs?
12. Do you think there is a need for a better understanding of Traditional health practices?
13. What are in your opinion the main challenges that health-care professionals face when dealing with patients with seizures?
14. What makes it easier (or will make it easier) for you as a health-care professional to deal with patients with seizures?
15. What is in your opinion the main challenges faced by patients with seizures?
16. What do you think makes it easier (or will make it easier) for patients with seizures?  
Any final thoughts on the matter?

## Appendix C4: ES Survey for HCP

### Epilepsy Survey for Health Professionals

#### 1. INFORMED CONSENT

**PRINCIPAL INVESTIGATOR:** Anina du Toit (PhD Student)

**REFERENCE NUMBER:** REC-050411-032

**ADDRESS:** 10 Barella Street, Klein Windhoek, Windhoek, Namibia, 9000 **CONTACT NUMBER:** 081 149 0010

You are asked to participate in a research study conducted by Anina du Toit, a PhD student from the Psychology Department at Stellenbosch University. Results from this study will be contributed to dissertation research. You were selected as a possible participant in this study because you have been identified as a healthcare provider specializing in rendering services to patients suffering from seizures.

- \* 1. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part. This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. **PURPOSE OF THE STUDY:** This study aims to explore the perceptions and frustrations experienced by healthcare providers and traditional health practitioners in diagnosing and treating patients who experience seizures. For the purpose of this study, a healthcare provider is defined as an individual who is responsible for the diagnosing, treating and/or rendering of services to patients who experience seizures. **PROCEDURES:** If you volunteer to participate in this study, we would ask you to do the following things: Complete an anonymous survey consisting of 25 questions. Approximately 50 individuals will participate in this study. Data collection will be in the form of an online survey or electronic survey. Provision will be made for surveys to be completed in hard copy format. **POTENTIAL RISKS AND DISCOMFORTS:** The proposed study can be classified as low risk as the research will be conducted on a largely uncontroversial topic through a survey and semi-structured interviews. The participants are adults (health care professionals) and not considered to be a vulnerable research population. The research will compose of information that can be regarded as non-sensitive, such as opinion rather than personal information and will be collected anonymously through a mail survey and semi-structured interviews. **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY:** Most of the studies that have been conducted on seizures have taken place in developed countries, while developing countries such as Namibia have received less focus. A study of this nature has not been conducted in Namibia, and it is possible that the knowledge obtained from this study could be used to offer suggestions on how healthcare providers could manage the challenges they face in diagnosing and treating seizure patients. There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Namibia, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the perceptions and frustrations experienced by healthcare providers in rendering services to patients suffering from seizures.

Please tick YES if you understand and agree with the above-mentioned.

Yes

No

\* 2. **PAYMENT FOR PARTICIPATION:** You will not be paid to participate in this study; participation is wholly voluntary and no reimbursement will be forthcoming. **CONFIDENTIALITY:** Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning a code instead of using the participant's name. Participants will have the right to review/edit audio recordings of interviews. Only the researcher and her supervisor will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the researcher's office and it will be appropriately destroyed and discarded once the study is completed. No confidential or identifying information will be used in the event that results from the study is published. Results from the study will be used to generate descriptive statistics only. **PARTICIPATION AND WITHDRAWAL:** You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, although it is not anticipated that any circumstances can arise that would warrant such withdrawal. **IDENTIFICATION OF INVESTIGATORS:** If you have any questions or concerns about the research, please feel free to contact the Principal Investigator: Anina du Toit on 081 149 0010 or Supervisor: Dr. Chrisma Pretorius on +27 21 808 3435. **RIGHTS OF RESEARCH SUBJECTS:** You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

Please tick YES if you understand and agree with the above-mentioned.

YES

NO

**Epilepsy Survey for Health Professionals**

**2. A: About yourself**

PLEASE PROVIDE AT LEAST ONE ANSWER TO EVERY QUESTION

\* 3. What is your age?

\* 4. What is your gender?

Female

Male

\* 5. Where do you practice, town?

\* 6. Which kind of patients do you see? Tick all boxes that apply.

I work with hospital inpatients

I work with hospital outpatients

My work is community-based (outside hospital)

I see private patients (self-funding/medical aid)

I see state patients

Other (please specify)

\* 7. What is your speciality? Tick all boxes that apply.

- Neurologist with special interest in epilepsy / Epileptologist
- General Neurologist
- Neuropsychology
- Neuropsychiatry
- Psychiatry
- Psychology
- Psychotherapy
- General/Internal Medicine
- General Practice
- Social Work
- Traditional Healer
- Clinical Officer in General Medicine
- Clinical Officer in Psychiatry
- Nurse Mental Health
- Epilepsy nursing
- General Nursing
- Counselling

Other (please specify)

\* 8. Tell us about your work with patients with epilepsy. (Please tick all boxes which apply)

- I refer patients to others for diagnosis when I suspect epilepsy.
- I personally diagnose epilepsy.
- I communicate the diagnosis of epilepsy.
- I refer patients with epilepsy to others once I have made the diagnosis and explained it to the patient.
- I recommended treatments for epilepsy.
- I arrange treatments for epilepsy.
- I provide psychological treatment for epilepsy (beyond explaining the diagnosis).
- I provide psychiatric treatment for patients with epilepsy.
- I prescribe medicines for patients with epilepsy.
- I provide follow-up for patients with epilepsy.

\* 9. Please give an estimate of the number of patients who you diagnose with epilepsy per year? (Please select best answer)

- 0
- 1-5
- 6-10
- 11-20
- >20

\* 10. Please give an estimate of the number of patients with epilepsy under your current care? (Please select best answer)

- 0
- 1-5
- 6-10
- 11-20
- 20-50
- >50

\* 11. Which of the following options best describes your level of confidence about diagnosing epilepsy? (Please select one option)

- I do not really know how to diagnose epilepsy.
- I am aware of the appearance of epileptic seizures but I am uncertain about the diagnosis and do not know how to explain it to patients.
- I have seen epileptic seizures in real life, on EEG recordings, am familiar with the typical appearance of epileptic seizures and make the diagnosis occasionally.
- I have seen epileptic seizures in real life, on EEG recordings, am familiar with the typical appearance of epileptic seizures and make the diagnosis often.

\* 12. Which of the following options best describes your level of confidence about treating epilepsy? (Please select one option)

- I do not know how to explain epilepsy or how to treat this disorder.
- I know how to explain the diagnosis of epilepsy but do not know how to treat this disorder.
- I know how to explain the diagnosis of epilepsy and what the treatment options are but I am not experienced with arranging or offering treatment.
- I am very familiar with epilepsy and how to explain the diagnosis, propose treatment options and arrange treatment.
- I am very familiar with epilepsy and provide treatment for the disorder.

\* 13. As how familiar with psychotherapy would you describe yourself? (Please select one option)

- I do not know anything about psychotherapy or how it might work for epilepsy.
- I know about psychotherapy in theory but could not describe what it involved and how it might work.
- I know about psychotherapy, can describe the process in principle but not specifically in relation to epilepsy.
- I am well informed about a range of psycho-therapeutic approaches and can describe how different approaches could help patients with epilepsy.

**Epilepsy Survey for Health Professionals****3. B: About epilepsy in your area**

PLEASE PROVIDE AT LEAST ONE ANSWER TO EVERY QUESTION

\* 14. What do you estimate is the gender distribution of your patients with epilepsy? (Please select best answer)

- I have only seen epilepsy in women.
- I have seen epilepsy more often in women than in men.
- I have seen epilepsy in as many women as in men.
- I have seen epilepsy more often in men than in women.
- I have only seen epilepsy in men.

\* 15. In your opinion, to what extent do the following aetiological factors play a role in the development of epilepsy?

	Never	Rarely	Sometimes	Often
Poverty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ethnic / racial discrimination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood emotional / physical abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood sexual abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bullying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School pressures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adulthood sexual trauma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family conflict / pressures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alcohol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accumulated life stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious and cultural factors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV and stigma from HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender based violence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personality disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Volitionally produced seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gender identity issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal sexuality issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Progressive brain disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic factors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Congenital conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Head Trauma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Epilepsy Survey for Health Professionals

**4. C: About your diagnostic service for patients with epilepsy**

PROVIDE AT LEAST ONE ANSWER TO ALL

\* 16. Which diagnostic tests do you have access to? (Please select all that apply)

- Routine EEG (30 minutes recording)
- Routine EEG with video (30 minute recording)
- Prolonged outpatient EEG without video (1-8 hour recording)
- Prolonged outpatient EEG with video (1-8 hour recording)
- Outpatient ambulatory EEG
- Inpatient video-EEG (longer than 8 hours)
- Video-EEG in patients' homes
- Neuropsychological testing
- Postictal prolactin measurement
- Computed tomography of the head
- Magnetic resonance imaging of the head
- Tilt-table examination
- Routine heart recording (EEG/EKG, less than 5 minutes)
- 24 hour ambulatory heart recording
- 24 hour ambulatory blood pressure recording
- Long-term heart rhythm monitoring with implantable device

\* 17. Roughly what proportion of your patients have a diagnosis of epilepsy supported by the "gold standard" of the recording of a typical attack with EEG?

- 0%
- 1-10%
- 11-20%
- 21-30%
- 31-40%
- 41-50%
- 51-60%
- 61-70%
- 71-80%
- 81-90%
- 91-100%

\* 18. How often will your patients undergo:

	Never	Rarely	Sometimes	Always
A psychiatric or neuropsychiatric evaluation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A psychotherapeutic assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A psychological assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuropsychological testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Epilepsy Survey for Health Professionals

**5. D: About your management of epilepsy**

PLEASE PROVIDE AT LEAST ONE ANSWER TO EVERY QUESTION

\* 19. Do you typically communicate the diagnosis of epilepsy to your patients?

- Yes  
 No

20. If not, who typically first communicates the diagnosis of epilepsy to your patients? (Please select one answer)

- Neurologist  
 Nurse  
 Family doctor  
 Psychologist  
 Neuropsychologist  
 Counsellor/ Therapist  
 Psychiatrist  
 Neuropsychiatrist  
 Clinical Officer General Medicine  
 Clinical Officer Psychiatry  
 Medical Officer (Government hospital)

\* 21. How is the diagnosis of epilepsy usually communicated to the patient? (Please select all that apply)

- Letter to the patient  
 Face to face explanation to the patient  
 Face to face explanation to the patient's family if present  
 Letter to another healthcare practitioner  
 Leaflet about epilepsy for patient/family  
 Patient referral to websites about epilepsy  
 Patient referral to self-help groups  
 Diagnosis of epilepsy is not explicitly communicated

\* 22. Which of the following statements would you typically include in your discussion of epilepsy?  
(Please select all that apply)

- I do not discuss the diagnosis of epilepsy with patients.
- I say that the events are caused by electrical discharges in the brain.
- I say that the events are a response to stress.
- I say that the events may be a sign of suppressed traumas from the past or ongoing conflicts.
- I say that epilepsy are often the result of trauma.
- I say that the cause of epilepsy are complicated and that there may be predisposing factors, factors which first started attacks and factors which maintain the problem.
- I say that the events do not cause any lasting damage.
- I say that the events are not a form of possession by evil spirits and that it is a medical condition.
- I say that the person is not deliberately producing those events.
- I say that the person is not aware of epilepsy.
- I say that epilepsy is a mental health problem.
- I say that anti-epileptic drugs do work for epilepsy.
- I say that anti-epileptic drugs may have side-effects which need to be monitored regularly.

\* 23. Which of the following reasons would lead you to continue following patients up after the communication of the diagnosis? (Please select all that apply)

- I do not follow patients with epilepsy up once I have made the diagnosis
- I follow up patients who continue to doubt the diagnosis.
- I follow up patients with epilepsy and additional mental health problems.
- I follow up patients who use anti-epileptic drugs.
- I follow up patients with epilepsy whose seizures have stopped but could return.
- I follow up patients who have not yet engaged with a psychiatric / neuropsychiatric service.
- I follow up patients who have not yet engaged in psychotherapy.
- I follow up patients with epilepsy for whom I have prescribed medication.
- As a rule I offer all patients with epilepsy at least one follow up appointment after I have explained the diagnosis.

\* 24. Which of the following treatment options would you consider the most effective treatment for epilepsy? (Please select all that apply)

- Individual psychological treatment (Cognitive Behavioural Therapy or other forms of psychological treatment)
- Group psychotherapy
- Antidepressant drugs
- Antipsychotic drugs
- Anti-epileptic drugs
- Beta-blockers
- Benzodiazepines
- Religious ceremonies including exorcism of evil spirits
- Traditional healing practices
- Placebo drug treatment
- Herbal mixtures
- Homeopathic preparations
- Hypnosis
- Acupuncture
- I do not think any treatment is effective
- Other (please specify)

\* 25. Is psychotherapy (Cognitive Behavioural Therapy or other forms of psychological treatment) available in your area? (Please tick all that apply)

- No psychotherapy is available in my area
- Psychotherapy is available for private patients
- Psychotherapy is available for publicly insured patients
- Psychotherapy is available via telemedicine / tele health / internet-based services
- Other (please specify)

\* 26. How often do you refer a patient with epilepsy for psychological treatment? (including those who will fail to attend)

(Please select one option)

- Never
- Rarely
- Sometimes
- Often
- Always

\* 27. What is your opinion regarding the role of Traditional Health Practitioners (THPs) in the treatment of seizures?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
THPs can treat seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
THPs can play a supportive role in the treatment of seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There should be more collaboration between doctors and THPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I will refer a patient to a THP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Culture plays a role in the manifestation of seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seizures can only be treated by modern western medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some seizure patients prefer to be treated by THPs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I will never refer a patient to a THP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
THPs can diagnose seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Epilepsy Survey for Health Professionals

**6. E: About the health service you work in**

PLEASE PROVIDE AT LEAST ONE ANSWER TO EVERY QUESTION

\* 28. May patients you see receive state disability benefits because of their epilepsy?

- Yes
- No
- Unsure

\* 29. Please estimate the frequency with which patients will have difficulties to access your diagnostic or treatment services for epilepsy for the following reasons:

	Never	Rarely	Sometimes	Often
Illiteracy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Language / communication difficulties with healthcare professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with travel / geographic access to healthcare provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of money for tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of money for appointments with non-specialist healthcare professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of money for appointment with seizure expert	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of accessible healthcare practitioners who know about ES	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of psychological treatment services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of money for psychotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of money for drug treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stigma associated with epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of referral system to seizure experts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of liaison between traditional healers and health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of popular awareness of epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to information resources about epilepsy (such as leaflets / internet)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of intellectual capacity (for instance because of intellectual disability)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

30. Please add any comments you believe are relevant but have not been asked.

**Appendix D1: Informed Consent for THP re Seizures**

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CONSENT TO PARTICIPATE IN RESEARCH

SEIZURES: THE PERCEPTIONS AND FRUSTRATIONS OF HEALTHCARE PROVIDERS AND  
TRADITIONAL HEALTH PRACTITIONERS IN NAMIBIA

NHREC REGISTRATION NUMBER: REC-050411-032

PRINCIPAL INVESTIGATOR: Anina du Toit (BA Hons Psychology)

ADDRESS: 10 Barella Street, Klein Windhoek, Windhoek, Namibia, 9000

CONTACT NUMBER: 081 149 0010

You are asked to participate in a research study conducted by Anina du Toit, a PhD student from the Psychology Department at Stellenbosch University. Results from this study will be contributed to dissertation research. You were selected as a possible participant in this study because you have been identified as a traditional health practitioner specializing in rendering services to patients suffering from seizures.

Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Research Ethics Committee: Human Research at Stellenbosch University (Humanities)** and will be conducted according to the ethical guidelines and principles of the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

## PURPOSE OF THE STUDY

This study aims to explore the perceptions and experiences of healthcare providers and traditional health practitioners in diagnosing and treating patients who experience seizures. For the purpose of this study, a healthcare provider is defined as an individual who is responsible for the diagnosing, treating and/or rendering of services to patients who experience seizures. A traditional healthcare practitioner is defined as an individual who treats or renders traditional healthcare practices to a person who experiences seizures. This study can contribute significantly to the knowledge gap between traditional and conventional healthcare provision in an attempt to improve quality of care to seizure patients in Namibia. Second, this study could potentially contribute to a more collaborative relationship between HCPs and THPs in this country. Third, the proposed multi-layered investigation could also inform government policies regarding the provision of adequate healthcare infrastructure and regulatory bodies that recognize the role of THPs in healthcare provision. Finally, the inclusion of the perspectives of THP's could contribute significantly to the rendering of culturally inclusive healthcare services for seizure patients in order to manage this condition effectively.

## PROCEDURES

If you volunteer to participate in this study, you would be asked to do the following things:

- You will be invited to partake in a once-off semi-structured interview that will last approximately 20-45 minutes, during which you will talk about your perceptions and experiences in the course of diagnosing and treating patients suffering from epilepsy and/or seizures.

The study will be conducted at a time and place that suits you. Approximately 50 individuals will participate in this study. Semi-structured interviews will be conducted with 15-25 selected participants. Interviews will commence with the completion of a biographical questionnaire. This will be followed by a semi-structured interview, consisting of questions that relate to your perceptions and experiences as a traditional health practitioner rendering services to patients suffering from epilepsy and/or seizures. The interviews will be conducted one-on-one and I (a Psychology PhD student) will be conducting the interviews. Each interview will be approximately 20-45 minutes long. With your permission, the interview will be audio-recorded so that it can be transcribed verbatim for the data analysis. The participant retains the right to review/edit all recordings.

## POTENTIAL RISKS AND DISCOMFORTS

The proposed study can be classified as low risk as the research will be conducted on a largely uncontroversial topic through a survey and semi-structured interviews. As a Traditional Health Practitioner you are an adult and not considered to be a vulnerable research population. The research will compose of information that can be regarded as non-sensitive, such as your opinion rather than

your personal information and will be collected anonymously through a mail survey and semi-structured interviews.

#### POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Most of the studies that have been conducted on seizures have taken place in developed countries, while developing countries such as Namibia have received less focus. A study of this nature has not been conducted in Namibia, and it is possible that the knowledge obtained from this study could be used to offer suggestions on how healthcare providers could manage the challenges they face in diagnosing and treating seizure patients.

There will be no direct benefit for taking part in this study. However, this study is one of the first of its kind in Namibia, and it is thus possible that the findings of this study could be published as a scholarly article in a peer-reviewed journal. This could lead to a greater understanding of the perceptions and experiences of healthcare providers in rendering services to patients suffering from seizures.

#### PAYMENT FOR PARTICIPATION

You will not be paid to participate in this study; participation is wholly voluntary and no reimbursement will be forthcoming.

#### CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning a code instead of using the participant's name. Participants will have the right to review/edit audio recordings of interviews. Only the researcher and her supervisor will have access to the information obtained during the study. All the collected data will be kept secure in a locked cabinet in the researcher's office and it will be appropriately destroyed and discarded once the study is completed.

No confidential or identifying information will be used in the event that results from the study are published. Results from the study will be used to generate descriptive statistics only.

#### PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, although it is not anticipated that any circumstances can arise that would warrant such withdrawal.

## IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact the Principal Investigator: Anina du Toit on 081 149 0010 or Supervisor: Dr Chrisma Pretorius on +27 21 808 3435.

## RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

## SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

By signing below, I, \_\_\_\_\_ agree to take part in a research study entitled Seizures: Perceptions and Experiences of Namibian Healthcare Providers and Traditional Health Practitioners in Namibia.

I declare that:

- The information above was described to me in a language I understand.
- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I have been given a copy of this form.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2017.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Signature of witness

**SIGNATURE OF INVESTIGATOR**

I (*name*) \_\_\_\_\_ declare that:

- I explained the information in this document to \_\_\_\_\_
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_ 2017.

\_\_\_\_\_  
Signature of investigator

\_\_\_\_\_  
Signature of witness

**Appendix D2: Biographical Questionnaire for THP**

Biographical information

Instructions: Please fill in your biographical information. Indicate your choices by circling the correct option.

Age: .....

Gender: Male/ Female

Ethnicity: African/Coloured/White/Other\*

If other, please specify:

.....

Marital Status:

.....

Home language:

.....

Email address:

.....

Contact number:

.....

Your qualifications/training:

.....

Do you specialize in any field?

.....

How long have you been a traditional health practitioner?

.....

**Appendix D3: Semi-Structured Interview Questions for THP re Seizures**

1. Do you treat patients who experience seizures?
2. Could you explain what you see as a 'seizure'?
  - What is your definition of a 'seizure'?
3. Are there specific causes/reasons why people get seizures?
  - What are these causes/reasons?
4. How do you explain to your patients what is happening when they get a seizure?
  - Do people accept/understand your explanation for their seizures?
5. Can you treat a patient who gets seizures?
  - Can you help all people who get seizures or only some?
  - How do you decide whom you can help and who not?
6. How do you treat seizures?
  - How long does it take to treat the seizures?
  - What type of medicine do you use?
7. Is the treatment successful?
  - How do you know it is successful?
8. Do you send the patient to a hospital when they get seizures?
  - Do you know how they treat the patient at the hospital?
9. Do you ever send the patient to another healer?
  - Do other healers send patients to you?
10. Do you ever send the patient to a western doctor or psychologist?
11. Do you ever get referrals from western doctors or psychologists?
12. Do you think that western medicine can treat seizures?
13. What are some of the problems you experience when you work with seizure patients?
14. What do you think will make it easier for you to treat seizure patients?
15. What do you think are the biggest problems for people who get seizures?
16. What do you think will make it easier for people who get seizures?
17. Do you know of any other healers that work with seizure patients?

### **Appendix E: Participant Profiles**

This section provides a description of the HCPs that were interviewed during the present study. Each participant is referred to by his/her participant code in order to ensure confidentiality. The following descriptions provide a brief summary of each HCP's demographic information, qualifications and expertise, as well as my personal reflection on the interview process.

#### **A1**

P1 is a 39-year-old African male with 6 years' experience as a neurologist. He currently resides in Windhoek, Namibia. The interview was conducted at his consulting rooms. This was my first interview, and I felt quite nervous, although his easy and friendly manner quickly put me at ease. P1 welcomed the opportunity to contribute towards the study and indicated that there is a need for more research into neurological conditions. The interview lasted well over 40 minutes and the information gleaned from P1 proved to be of great value to the study. He was very knowledgeable about the diagnosis and treatment of PNES and was able to highlight some of the challenges encountered by patients who rely on government healthcare services. His confidence and knowledge were repeatedly reflected in his answers. His sincere wishes at the end of the interview boosted my confidence, and I felt exhilarated at the success of my first interview.

#### **A2**

P2's interview was originally scheduled to take place in his practice. However, upon my arrival, his receptionist informed me that he was not there. She was able to reach him on his mobile phone, and the interview was rescheduled for a later time at my office. He was very apologetic when we finally managed to meet. P2 is a 38-year-old African male with a PhD in clinical psychology and a particular interest in forensic psychology and psychopathology. Even though our time was limited, P2 did not rush the interview and put great thought into his answers. He provided fascinating insights into the cultural aspects of mental health and epilepsy. He also explained the different approaches to treatment from an African perspective. I was engrossed with what P2 had to say and felt that I could learn a great deal from him due to his extensive knowledge and wisdom.

**A3**

P3 is a 47-year-old white female with 21 years' experience as a GP. She has extensive knowledge of psychiatry and psychology and often renders psychiatric services to inpatients. This interview was quite challenging to conduct, as there was a lot of background noise, possibly due to building operations in and around her practice. She was also very hesitant and soft-spoken in her replies, which made it difficult to follow the interview. Notwithstanding these challenges, P3 was very friendly and accommodating and seemed genuinely interested in the topic of the study. This was my first interview with a GP, and it was interesting to note how approaches to PNES differed between the various professions. P3 often elaborated on the interview questions through the use of case studies and was able to illuminate the techniques applied when working with patients in a hospital setting.

**A4**

P4 is a 57-year-old white male with 30 years' experience as a GP. P4's interview was conducted at his practice while he was busy seeing patients. As a result, this interview felt slightly rushed, and I got the impression that he did not have a lot of time to spare. P4 answered the interview questions in a very brief and to the point manner and seldom elaborated on his answers. It seemed that he was largely unfamiliar with the diagnosis of PNES or the possibility that psychotherapy may be used as an alternative treatment method for seizures. Although this interview was hard to conduct, it gave me some insight into the complexities of a large and bustling GP practice. It also highlighted the challenges experienced by GPs due to the lack of time they have with each patient and the resultant frustration when a patient fails to respond to conventional treatment.

**A5**

The fifth participant was interviewed at her practice. P5 is a 37-year-old Coloured female who has been practising as a clinical psychologist for the past 10 years. This interview was effortless as she was very excited to participate in the study and required little probing when she answered the questions. P5 put great effort into her answers and elucidated the role of the psychologist in the treatment of PNES. She offered unique insights into the challenges encountered by her profession in securing training and continuous professional development opportunities. I truly appreciated her positive attitude and passion for her job. P5 was an inspirational HCP to interview due to

her extensive community involvement and infectious optimism regarding her country and her people.

#### **A6**

For my sixth interview, I met P6 at her consulting rooms which were situated in an old historical building that emanated peace and tranquillity. P6 is a 47-year-old, white, female psychiatrist and is known for her ability to work with children and teenagers. The topic seemed to be quite difficult for her as she acknowledged that she did not have a lot of experience with ES and PNES patients. However, she was compliant and answered the questions to the best of her ability. The interview was conducted in her second language (English), and she sometimes appeared hesitant and unsure about her answers. Although this interview was harder to conduct than some of the others, I found that these challenges might reflect some of the difficulties encountered by HCPs and patients, for example, lack of knowledge and awareness of the disorder, as well as communication difficulties between physicians and patients.

#### **A7**

P7 is a 37-year-old, white, female psychiatrist. The interview with P7 was conducted at her practice, and she seemed relaxed and confident to talk about the topic. P7 was very knowledgeable about PNES and spontaneously shared some of her earlier experiences as an intern. This elucidated the difficulties and frustrations encountered by HCPs when confronted with a disorder that is relatively unknown and difficult to treat. I also gained valuable information on the current state of healthcare infrastructure in Namibia and how this compares to South Africa. This was a pleasant and effortless interview, and I left feeling motivated and buoyed by her positive energy and no-nonsense approach.

#### **A8**

For my eighth interview, I met with P8 at his consulting rooms in Windhoek. P8 is a 57-year-old white male who has been practising as a GP for the past 30 years. Although he admitted that he does not regularly encounter patients with PNES, he was able to describe certain cases where PNES may have been the cause of the symptoms. He shared some of his frustrations regarding the referral of patients to psychologists and how this sometimes creates misunderstanding between HCPs. P8 indicated that he had a particular interest in psychiatry and psychology and often took the time to engage

patients in talking about their difficulties. This interview was pleasant and relaxed and highlighted the positive impact that a GP may have on patients given sufficient time and interest in the patient's circumstances. After completing this interview, I felt more positive about the role of GPs in the management of PNES. I also realised that time constraints in a GP practice might often contribute to the lack of timely diagnosis and effective treatment of PNES.

#### **A9**

P9 is a 60-year-old African female who had been practising as a GP for the past 30 years. I conducted the interview at her consulting rooms while she was busy seeing patients. This interview felt rushed, and I was under pressure to gather as much information as possible in a very brief period. This GP indicated that she specialised in occupational health and are seldom exposed to patients who suffer from epilepsy. I could tell that P9 was interested in assisting me, but she seemed preoccupied and sometimes struggled to express her opinion clearly. This was a more difficult interview to conduct, and I left feeling a bit despondent. It dawned on me that GPs operate under immense time pressure and seldom have sufficient energy and time to struggle with a patient who does not respond to conventional treatment.

#### **A10**

P10 is a 52-year-old white male GP. This interview was conducted after-hours at his home because he felt that he would not have sufficient time during business hours to focus on the interview questions. He appeared very accommodating and relaxed although his answers reflected a short, no-nonsense approach to the challenges posed by patients with medically unexplained symptoms. He elucidated the role of the GP in disorders of this type and how different professionals contribute to the diagnosis and treatment of PNES. Once again, I got the impression that GPs in large and very busy practices seldom have sufficient time to struggle with patients that do not seem to respond to treatment. This interview was quite effortless as he required little probing to answer the questions and was able to contribute valuable knowledge to the role of the GP during the diagnostic process. I could also tell that P10 had lots of pride in his role as GP and considered his profession to be the mainstay of healthcare provision to the public.

**A11**

The eleventh participant was a 28-year-old Coloured female who had been practising as a psychological counsellor for the past five years. P11 was by far the youngest and most inexperienced participant in the study. She was, however, very excited to participate, although she appeared quite nervous. P11 has been exposed to a large variety of mental health patients across the country and in a government environment. It was a pleasure to interview her as she willingly elaborated on her answers and was able to lend a different perspective on the provision of treatment from a young and inexperienced viewpoint. She provided some valuable insights regarding the role of government in healthcare provision, and the challenges encountered by patients who rely on state-funded services. This interview left me with the impression that younger HCPs have an important role to play in the future of mental health services in Namibia.

**A12**

P12 is a 58-year-old white male psychiatrist with 32 years of experience. I was very nervous prior to this interview as P12 is one of the most prominent service providers in the country. However, he was so warm and welcoming that I immediately felt at ease. He was also very knowledgeable about PNES and shared his experiences and opinions in a well-structured and informative manner. This interview flowed very well, and I gained valuable information for the study. I truly felt that I could learn a great deal from P12 due to his extensive knowledge on the subject. His easy-going and confident nature was reflected in his approach to difficult diagnoses. Meeting P12 was an informative experience, and I left the interview feeling positive and empowered by his wisdom and knowledge.

**A13**

For my thirteenth interview, I met with P13 at his consulting rooms. P13 is a 35-year-old African male who has recently qualified as a neurologist. Although this interview was harder to conduct due to language difficulties, English is not his first language; it flowed well. He appeared very knowledgeable about PNES and contributed valuable insights regarding the referral practices amongst HCPs in Namibia. He put great thought into his answers and did not rush the interview, despite his busy schedule. He appeared very interested in this study and gladly volunteered information. Despite the

communication barrier, I felt that I had gained valuable information from P13 and that the interview was successful.

#### **A14**

P14 is a 53-year-old white male GP with extensive knowledge of neurological disorders and somatic experiences. During this interview, he seemed more nervous than I did, although he became more comfortable and willing to share his experiences as the interview progressed. He admitted that he seldom became involved in the diagnosis and treatment of PNES and preferred to make use of specialists in this regard. He was, however, instrumental in explaining how patients may react and process a diagnosis of PNES. He also elucidated the influence of public perception and the lack of knowledge regarding mental illnesses. I enjoyed this interview and his humorous and sometimes cynical view of conventional medicine and its potential pitfalls.

#### **A15**

I conducted the interview with P15 during our lunch break at a continuous professional workshop. He is a 60-year-old white male with 34 years of experience as an educational psychologist. The insights gained from this interview illuminated the challenges in working with children and especially their parents, where a difficult diagnosis is concerned. P15 was very hesitant and soft-spoken but gladly volunteered his experiences in working with the kids. The tone of the interview was quite solemn, and one could see that he is very passionate about his work. His compassionate nature shone through in his responses and created a realization that there are so many complexities to this disorder that is not visible at first glance.

#### **B1**

For this interview, I met a 53-year-old white female GP at her consulting rooms. She seemed nervous when I requested to record the interview but gradually relaxed and became more verbal and animated. She indicated that she did community work among a small tribe in Northern Namibia and seemed open to the role of culture and traditional healers in the treatment of seizures. She stated that she often makes the initial diagnosis of epilepsy but prefers to make use of a specialist in Cape Town to confirm her suspicions. She was very interested in the research and offered her help in the event that I needed more information. Although she seemed a bit reticent at the start of the

interview, she warmed up considerably, and I left feeling positive and motivated to continue the process.

## **B2**

Interview 17 took place at the HCP's consulting room during his lunch break on Friday. He is a 61-year old white male with many years in private practice. He is a very warm, calm and gentle person and I have known him for years. He spoke confidently about the topic and freely elaborated on the questions from the interviewer. He did not seem perturbed by the recording and appeared completely relaxed. He had a lot of knowledge to share and even made some suggestions on how to improve the study. He made some interesting observations about how parents react when their children are diagnosed with epilepsy. It was a pleasure to listen to him. He seemed open about the role of THPs in the treatment of seizures and indicated that it would be interesting to have more contact and collaboration with THPs.

## **B3**

This interview took place directly after the previous one, so I was more prepared for it. This 60-year-old white male GP is always entertaining. I have known him for a long time, so the interview was relaxed and open. He specializes in psychiatry and willingly shared his opinions. He agreed to the recording of the interview but was necessarily comfortable with it. He had a lot of knowledge about seizures and some experience of THPs who treated people with epilepsy. He was willing and able to answer all the questions. It was the second time that I interviewed him, and he is very considerate and organised. All the necessary document is was completed upon my arrival, and he seemed prepared for the interview. He is very accommodating, encouraging and made me feel welcome.

The next five interviews were conducted in Rehoboth, a town 90km south of Windhoek. The population consists of small-scale farmers, artisans and people that commute to Windhoek on a daily basis for reasons of employment. The preferred language is Afrikaans, and most people are of mixed heritage. I am familiar with the community and many of the GPs that work there. As part of my job as Psychological Counsellor, I have been travelling to Rehoboth once a week to see clients since 2013. Most of the GPs that I interviewed refer to us on a regular basis and we have a good working relationship.

**B4**

The first interview on this Monday morning was with a Zimbabwean GP, aged 43, male and Black. He was very late for the interview, and the patients were already lined up outside. He was present when I did a presentation to the GPs in Windhoek about the findings of the PNES part of the study. So, he was familiar with my research and very supportive. He appeared relaxed and knowledgeable and was able to provide valuable information on how seizures are treated in Zimbabwe. It was a good interview, and even though I felt a bit rushed, I was able to garner a lot of information from him. He appeared unperturbed by the growing number of patients outside and took his time to bring his point across. It was good talking to him, and I raced out to catch the next GP.

**B5**

The next interview was with a mixed race male GP, aged 50. He was kind enough to squeeze me in when another GP cancelled at short notice, so I did not want to make him wait for me. He also did not make me wait even though there were patients in his waiting room. He, however, appeared a bit tense but nevertheless provided me with information about how the diagnosis and treatment of seizures are performed in the state facilities. Although he indicated that he does not see a lot of patients with epilepsy, he knew enough about the disorder to give some valuable insights. He also elaborated on the increasing rate of TB patients and the concerns regarding diabetes in the community. He alerted me to the fact that many people in Rehoboth live under the breadline and are dependent on state healthcare facilities. It was an interesting conversation, and I left feeling better informed about Rehoboth and how the community functions.

**B6**

The following interview was also with a Zimbabwean doctor. This 39-year-old male was not seeing patients on the day but postponed a trip to Windhoek to make time to see me. I did not have long to wait, and he definitely did not seem in a rush. This was the longest interview so far, close to an hour. He was very welcoming and friendly. He appeared to enjoy the interview, freely elaborating on questions and offering advice. Although he spoke in English, he did seem to have mastered some Afrikaans terms. This would seem essential in a community where most of the residents only speak Afrikaans. He informed me of the role of 'smeer oumas' in the Rehoboth and mentioned that they regularly refer people to him. The 'smeer oumas' can probably be seen as the equivalent

of a traditional healer in the black communities. It was a good interview, and I moved on to the final two GPs.

### **B7**

This time I interviewed a Black GP, aged 42 that hails from the Democratic Republic of the Congo. His home language is French, but his English is excellent. He was very professional and to the point. I did not have to wait for him, and he appeared well informed and interesting. It would have been nice to spend more time with him, but he also had a full waiting room. He spent some time in state health facilities in Namibia and knew how it operated and that the care is often no up to standard. He was also willing to elaborate on the perceptions regarding epilepsy in the DRC. It was another good interview, and I appreciated his willingness to see me even when he was swamped.

### **B8**

This was the final interview of the day, and it was after 14h00 already. Luckily it was a GP that I have known for a long time but haven't seen in a while. He is of mixed race, aged 46. He was very warm and excited to see me again. He is a very calm, quiet person but has been in the business for a long time. He knew the topic and stepped through it like a real professional. It was enjoyable to talk to him, and he made me feel welcome and special. He also had a busy day of patients but never rushed and took his time to explain how things worked in Rehoboth. It was good to see him again, and he had always been very supportive of the work we do in Rehoboth.

All in all, it was a good day in Rehoboth. It is an extraordinary community with many psychosocial problems. Things do work differently in Rehoboth, and it was good to get another perspective on how PWE are treated and perceived.

### **B9**

I conducted this interview with a 49-year-old white German doctor. I interviewed her for the PNES part of the study too, so it was nice to talk to her again. She is incredibly compassionate and has a particular interest in psychiatry. She counsels her own patients, and it is evident how she can do it. She is just so understanding and warm one cannot help but open up to her. She is very up to date with alternative therapies and pointed me in the direction of some herbalists and naturopaths that the German community in Namibia consults on a regular basis. I need to think how I can bring that into the dissertation because I do believe that they can add value and some interesting

insights. She used case studies that vividly illustrated some interesting aspects of epilepsy and how she contends with it. It was a long interview and very good. She made me think about a whole lot of things and once again made me aware of the complexities in what I am trying to achieve. I left the interview feeling thoughtful, and it was almost too much information to process in a single sitting.

### **B10**

The tenth interview for this round of data collection was performed after hours at the HCP's consulting room. I have known him for a while, and he was very gracious and willing to participate. This 53-year-old male, White HCP has practised in various places in Namibia and South Africa. He had a wealth of information to share and was very entertaining. He was frank and open about the current situation in Namibia and how the state healthcare system operates. He has experience working in the rural areas of Namibia and also worked in government for a while. He was well-prepared, volunteered information and made some very valuable suggestions regarding the research. It was exceptional to have time with him, he understood exactly the challenges I face during this process and some of the questions I need to address. In talking to him, I regretted not recruiting him for the PNES part of the study. He had come across this often as part of his work in the rural areas in South Africa. All in all another good interview and I walked away feeling a richer person for seeing him.

### **B11**

This was a fascinating interview. It was conducted with a gynaecologist and the only fertility specialist in Namibia. He treats people from all over Namibia and even Angola. He had to postpone the first appointment due to ill health but requested a second opportunity. He thanked me for coming to see him! I was quite surprised. He attended a CPD event for HCPs where I did a presentation of the PNES findings. He wanted to know more about PNES and then continued to educate me on the role of epilepsy in pregnant women and possible birth complications. This was truly fascinating and brought some insight into one of the leading causes of epilepsy in children in SSA. He was also able to highlight the difficulties in referral practices between HCPs. He took his time and never appeared rushed or under pressure. I felt quite special that a man of such calibre would take the time to pursue an interview with a student. He greeted me warmly at the end of the meeting and thanked me for my time. I left feeling both special and humbled by the grace and empathy of this man.

**B12**

This interview with one of the neurologists really lifted my spirits! I interviewed him for the PNES part of the study too, and at that point, he had only been in Namibia a couple of months and was probably still finding his feet. He originally hails from Zimbabwe. This interview was definitely the highlight so far. He was so incredibly welcoming, and his receptionist told me before the interview that he was actually looking forward to it! It was such a pleasure. He was encouraging, complimenting me on my progress, wanting to see the results of the previous study and genuinely took an interest. He spoke non-stop for 25 minutes and stepped through the interview as though he had memorized the questions. I hardly asked anything, he anticipated the questions and walked me through it like a true professional! He jokingly asked me at the end of the interview when I am starting the next PhD? He warned me that I would be bored once this is done and that writing becomes addictive! Again, an excellent interview and I left feeling motivated and on quite a high.

The following two interviews were conducted in Okahandja. This town is 70 km north of Windhoek. The population is more urban than Rehoboth with many of the residents commuting to Windhoek on a daily basis. There is a big military base just outside of town. It is a gateway to the North and West of the country and houses many industries and factories although not on the same scale as Windhoek.

**B13**

The thirteenth interview was conducted with 34-year-old White male GP in Okahandja. He was one of the interview volunteers from the CPD event that was hosted in Windhoek for HCPs. The interview took place before working hours at a large GP practice in Okahandja. Several GPs work there as well as nursing staff, they have a day clinic and do minor surgeries. The practice is well organised and uses all the latest technologies. He was very interested in the research and wanted to learn as much as possible about PNES. It was a long meeting and a very good discussion. He illuminated his conversation with many case studies and appeared genuinely co-operative. He is a really friendly person and made me feel completely at ease. It was such a pleasure to talk to him! He added many valuable insights about all aspect of the study and I wished we had more time. I left him with a line of patients waiting for his services, as was the case in many of the other GP practices.

**B14**

This interview was also conducted in Okahandja and with a Black, female GP. Another bustling practice and people lining up outside. However, she did not seem perturbed and freely gave of her time. She is another recruit from the CPD event and appeared encouraging and open about the treatment and diagnosis of seizures in Namibia. She was able to add valuable insights into the shortcomings of the state facilities and the many frustrations experienced by GP's in private practice where that is concerned. It was an easy and relaxed conversation. She was also able to clarify some of the cultural issues in treating patients from diverse backgrounds. She does not originally hail from Namibia but unfortunately time did not permit us to explore her country of origin. She greeted me warmly at the end and wished me all the best. I had the feeling that she would have liked to spend more time but her work was pressing. Another good interview!

**B15**

This was the final interview of the second round of HCP interviews for the study. It was conducted with one of the Neurologists that practice in Windhoek. He also participated in the PNES part of the study and it was good to meet him again. He was gracious and friendly and welcomed me warmly. Given his busy schedule, I appreciated the fact that he was prepared to make time for me again. He did not appear at all rushed and answered the questions in the same easy and comprehensive manner as the previous time. He is very knowledgeable and was able to give his impressions in a comprehensive and detailed manner. He was also able to volunteer information on the state medical procedures and some of the shortcomings in that area. He appeared interested in the study and was very encouraging. It was a relief to finish this part of the data collection process and it ended on a good note.

The process of interviewing the various HCPs awakened a sense of sadness that so many professionals and patients are adversely affected by the state of the healthcare infrastructure in Namibia. At the same time, it also instilled some hope and optimism regarding the future of health interventions in this country. HCPs were hungry to contribute to a study of this nature and saw the positive benefits that could be derived from the results. This places a certain burden on the researcher to make the most of this opportunity and to deliver a product that would make Namibians and HCPs proud.

## **C1**

This was the first interview with one of the healers and I was quite nervous. I did not know what to expect and prepared myself for all eventualities. It was conducted with a 69-year-old female at her house in Katutura. She was dressed in traditional Damara dress and small kids swarmed all over the house. It was already dark and chilly, but although she appeared cautious at the start of the interview, she quickly warmed up towards me and opened up about the topic of discussion. We sat in her living room and there were no obvious signs medicine or some of the paraphernalia that I expected of a traditional healer. It was a very long interview, more than an hour recorded and continued even after the recording was stopped. I was invited to look at her photo albums, certificates, programmes of events and other memorabilia. She takes great pride in her work and seemed hungry for someone to listen to her. I did manage to get some good material for the study and it was definitely an interview that I will not forget. I left three hours later and was a bit scared to be alone in strange neighbourhood. She asked for some bread money and after parting with N\$ 250 she appeared pleased.

## **C2**

This second interview was conducted with a 72 year old, female Oshivambo healer. It was conducted at her house in the Ohalushu Village in the Ongha settlement, Ohangwena Region and I was accompanied by an Oshivambo friend. She was dressed in a light blue Oshivambo traditional dress with a brown leather jacket and there were no obvious signs of her profession in the room where we conducted the interview. Although she was a bit reserved at the start of the interview she answered all the questions. She seldom elaborated and did not offer any additional information beyond what she was asked. Her English was poor and I often had to rely on my friend to interpret some of her answers. She however, appeared friendly and although the interview was brief I did manage to collect some interesting material from her.

## **C3**

This 59 year-old mixed race female, is a gifted healer. She greeted me with a firm hand shake as she ushered me into the house. Her office was very spacious and it had a healing room in the corner where a bed was placed for her clients to lie down as she performs the healing. The bed is necessary because her clients would often fall asleep while she lay hands on them. A box of sanitary gloves was also placed next to the

bed. As we sat down, with a large table between us to conduct the interview, she was open and forthcoming with all the questions. She is above average height, with a very interesting choice in hairstyle and colour. Her hair was black on the sides and dark red on the top in somewhat of a pixie cut. The environment was calm and her body language was relaxed with open gestures of the arms and strong eye contact. I did not feel intimidated in any way and the conversation flowed easily. She appeared passionate about her healing experiences and the excitement often led her off the path of epilepsy. She is also extremely comical always joking in between the interview but all in all it was a very enlightening and new experience for me.

#### **C4**

The house of this 66-year-old, female healer Herero healer is located at the top of a hill in a busy and loud location with music and children playing in the street. She is a large and impressive woman and was very friendly and sincere when it came to explaining her past life as a healer. Her husband interceded during the interview, assisting with the language barrier. He was very open and humorous during the interview. He is one of the founders of the Namibian Traditional Healers Association and was very keen on participating in the research. This interview almost felt like a group discussion with myself, a friend and her husband actively participating in an open and spontaneous way. The interview was very interesting, it felt like we all knew each other and the conversation flowed well. We left feeling like old friends.

#### **C5**

This 73-year-old, male is a proud Oshivambo speaking man. He is based in Tsumeb and the interview was done over the phone. However, he was friendly and appeared well-spoken in his explanations of epilepsy. He often used words that I did not understand and I had to rely on the healer that translated to understand what he was saying. This was quite a novel experience but I understood most of what he was saying. I felt at a disadvantage, due to the fact that the interview was not done face to face. That personal connection and being able to observe another's movements and interactions is something I personally feel is vital in any form of interviewing. Nevertheless an efficient and informative interview that was quick and straight to the point.

## C6

This telephonic interview with a 42-year-old male healer started on a bit of a sour note. Due to the fact that his overall understanding of the purpose of the interview was not clear. He wanted to know who I was, how his number was found, why he was chosen and what he would benefit from the interview. During the biographical questionnaire, as I asked about his age and marital status, he appeared combative and frantically spoke in Otjiherero. He failed to understand the use of this information in the research study, he was more concerned about answering questions based on epilepsy and his views rather than who he is. Once we managed to sort out the misunderstandings and I was able to explain the purpose of the research and what was expected of him he was very forthcoming and vocal about his opinions and methods towards epilepsy. It was a good interview in the end and well worth the initial trouble to address his concerns.

## C7

The road to this 40-year-old Herero healer is a dusty path to a small shack-like house. He is a very tall and well-built man. As we took our seats under the shade of a tree, the interview was done with the assistance of a Herero translator. The healer explained that he has treated thousands of epileptic patients and therefore refers to himself as a *guru* in the field. He is so good in his craft that he has never failed in his healing process. The overall interview was insightful and somewhat intimidating. The translator explained that this healer could see an individual's entire background by just looking at them. He has power, granted by the Holy Spirit, to know what diseases or curses one might have by simply looking into a person's eyes. Despite the assistance of the translator, there was a smooth flow of questions and answers and I was able to gather some unique insights into the world of this healer.

## C8

This 46-year-old healer classifies himself as a spiritual herbalist, which was a new and different view of the causes towards epilepsy and the various treatment methods used, compared to some of the other interviews. The interview was done with the help of a translator whom I found to not deviate too much from the original message. This healer was very enthusiastic with his answers and would give detailed explanations about epilepsy, as he would receive visions, guidelines, words and advice from the Holy Spirit through prayer on what to do in the case of epilepsy. I was extremely impressed with his

level of patience to be interviewed via phone, as throughout the interview, the translator, a friend and I would engage in conversation while he remained on the phone for approximately an hour. All in all an effective, friendly and informative interview.

### **C9**

Being led into a cabin on a dusty path, this 50-year-old healer's office was decorated with feathers, chicken feet and various coloured ropes hanging from the ceiling. There was a red candle burning in the centre of the table and different coloured jars on display. He welcomed me with a friendly smile, however, I felt uneasy and uncomfortable. The interview began with the aid of a translator who explained the purpose of the research study and his role as a participant. There was good flow in the interview when I ask about his understanding of epilepsy. He quickly warmed up to his subject, and patiently explained how he treats patients with epilepsy. He enthusiastically explained about the various herbs he uses to treat epilepsy. As the interview continued, he would open various jars and containers and continue to reassure that we had no need to worry. All in all a very novel yet insightful session, although I have to admit that I was relieved when we reached the end of the interview.

### **C10**

The meeting with this healer was comfortable and less intimidating than some of the others this 30-year-old male, who originally hails from Malawi, was well dressed and refers to himself as a divine healer, specializing in deliverance. He is a member and Pastor to the Bread of Life Church in Khomasdal mostly healing those within the church. He was open and honest with his answers, basing all of his beliefs on God and faith. The atmosphere was very professional and the interview flowed very well. Being a divine healer in a foreign country has not been easy for the Pastor but he has always been hopeful and has grown in his profession. He made me feel comfortable with direct and relatable answers to my questions, which were concise and straight to the point.

### **C11**

This 65-year-old female healer of mixed origin is also lecturer in nursing and midwifery sciences. Her passion and faith towards being a Christian, is what has driven her towards the ministry of healing and deliverance. She is very busy juggling lectures and leading the Charismatic Community at Church. As she had an upcoming appointment, the interview felt a bit rushed, but she was very friendly and respectful. As

a proud academic she was impressed with the research topic and was very curious to read through the informed consent form and appeared pleased with the work. Even though the answers were short, I trust that they will add value to the Research.

## Appendix F1: Ethical Clearance 1



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### Approval Notice

#### Stipulated documents/requirements

03-Dec-2015  
du Toit, Anina A

**Proposal #:** SU-HSD-000546

**Title:** Psychogenic Non Epileptic Seizures: Namibian Healthcare Providers' Perceptions and Frustrations

Dear Mrs Anina du Toit,

Your Stipulated documents/requirements received on 14-Oct-2015, was reviewed and accepted.

Please note the following information about your approved research proposal:

**Proposal Approval Period:** 22-Sep-2015 - 21-Sep-2016

#### General comments:

Please take note of the general Investigator Responsibilities attached to this letter.

**If the research deviates significantly from the undertaking that was made in the original application for research ethics clearance to the REC and/or alters the risk/benefit profile of the study, the researcher must undertake to notify the REC of these changes.**

Please remember to use your **proposal number (SU-HSD-000546)** on any documents or correspondence with the REC concerning your research proposal.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2015 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 218089183.

Sincerely,

Clarissa Graham  
REC Coordinator  
Research Ethics Committee: Human Research (Humanities)

## Appendix F2: Ethical Clearance 2



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### APPROVAL NOTICE Response to Stipulations

25 August 2017

Project number: SU-HSD-004501

Project title: Seizures: The Perceptions and Frustrations of Healthcare Providers and Traditional Health Practitioners in Namibia

Dear Anina Du Toit

Your response to stipulations received on 5 June 2017 was reviewed and accepted by the REC: Humanities.

**Ethics approval period:** 26 April 2017 – 25 April 2018

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

**If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.**

Please use your SU project number (SU-HSD-004501) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

#### FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

If you have any questions or need further help, please contact the REC office at [cgraham@sun.ac.za](mailto:cgraham@sun.ac.za).

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

*National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.  
The Research Ethics Committee: Humanities complies with the SA National Health Act No. 61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2<sup>nd</sup> Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.*

**Appendix G: Turnitin Report**

Seizures Perceptions and  
Frustrations of HCPs and THPs  
in Namibia

*by* Anina du Toit

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**Submission date:** 24-Nov-2017 01:03PM (UTC+0200)

**Submission ID:** 503261665

**File name:**

86655\_Anina\_du\_Toit\_Seizures\_Perceptions\_and\_Frustrations\_of\_HCPs\_and\_THPs\_in\_Namibia\_79786\_1025097927.docx  
(110.88K)

**Word count:** 81708

**Character count:** 466557

## Seizures Perceptions and Frustrations of HCPs and THPs in Namibia

### ORIGINALITY REPORT

<b>11</b> %	<b>8</b> %	<b>7</b> %	<b>6</b> %
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Submitted to University of Lincoln

**Appendix H: Declaration of Language Editing**



Director: CME Terblanche - BA (Pol Sc), BA Hons (Eng), MA (Eng), TEFL  
22 Strydom Street Tel 082 821 3083  
Baillie Park, 2531 cumlaudelanguage@gmail.com

**DECLARATION OF LANGUAGE EDITING**

I, Christina Maria Etrechia Terblanche, hereby declare that I edited the research study with the title:

**Seizures: the Perceptions and Frustrations of Healthcare Providers and Traditional Health Practitioners in Namibia**

for **Anina du Toit** for the purpose of submission as a research study for examination. Changes were suggested in track changes and implementation was left up to the author.

Regards,

CME Terblanche

Cum Laude Language Practitioners (CC)

SATI accreditation nr: 1001066

Full member of PEG